## LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY

---

## REPORT OF THE INQUIRY BY THE SELECT COMMITTEE ON EUTHANASIA

# VOLUME TWO TRANSCRIPTS OF ORAL EVIDENCE

---

**JULY 1995**

---

*Darwin, 14 March 1995 PH1*

*Alice Springs, 20 March 1995 PH2*

*Darwin, 29 March 1995 PH3*

*Bathurst Island, 7 April 1995 PH11*

PH11-1 Nguiu Community 412

(Puruntatameri, Mr B.; Tungatalum, Mr H.; Tipiloura, Mr O.;

Puruntatameri, Mr E.; Gordon, Ms V.; Puruntatameri, Ms J.;

Babui, Mr E.; Puruntatameri, Ms T.; Mayer, Dr J.)

*Darwin, 10 April 1995 PH12*

PH12-1 Sebastian-Pillai, Dr B. 424

PH12-2 Berecry, Ms Y. 429

PH12-3 Ashby, Prof. M. 438

PH12-4 Hunt, Dr R. 458

PH12-5 Australian Medical Association, NT Branch 478

(Wake, Dr C.; Howard, Dr D.; Carson, Dr P.; Kilburn, Dr C.;

Lickiss, A/Prof. N.)

PH12-5 Campton, Ms P. - *In Camera* 512

PH12-7 Syme, Dr R. 513

PH12-8 Wood, Mr W. and Mrs R. 524

PH12-9 Zalcberg, Dr J. 532

select COMMITTEE **ON EUTHANASIA**

HEA**RING**

Tuesday 14 March 1995

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr John FLEMING, Director, SOUTHERN CROSS BIOETHICS INSTITUTE

**Note:** Edited and corrected transcript.

**Issued: Tuesday 21 March 1995**

---

**Mr POOLE:** Dr Fleming, thank you for your time in coming up to see us. It will probably help you to know that just prior to your coming in, we accepted a recommendation that the committee authorise that witnesses submitting evidence to the committee may publish or dispose documents or oral evidence submitted by them to the committee, unless otherwise determined. But at the same time, the committee would not want any publication of any questions etc. emanating from the committee to yourself. All right?

**Dr FLEMING:** Sure. I can publish my work in the way that I normally do. The point is that the discussions are in camera.

**Mr POOLE:** The format of the meeting is our usual format, in that we allow you whatever time ... How long do you think you need to make your presentation to us?

**Dr FLEMING:** Perhaps about 15 minutes or so. Not too long?

**Mr POOLE:** No, that is fine. Then we will go into a general questionandanswer session, if that is all right with you.

**Dr FLEMING:** Indeed. Thank you, Mr Chairman. And first of all, thank you for inviting me and for the privilege of appearing before you. Thank you also for the efficiency and kindness with which I have been dealt with by Pat Hancock, and the hospitality which I have so far enjoyed.

My position on this is from the interest of public policy. I take the position that we will never determine unanimously in the community the moral rightness or wrongness of voluntary euthanasia. Even after that discussion has taken place, people will divide. Therefore, from the public policy point of view, it is probably not productive to attempt to persuade the community to one position or the other, because you will not succeed. People will have positions on that based upon their own, personal philosophical and religious commitments, and they have to be respected.

I say philosophical and religious, because while the religious element is often brought up, the philosophical one is not. In modern moral philosophy, there are many schools of thought. There are those, for example, dominantly in parts of Australia at the moment, that represent the utilitarian school of thinking based upon John Stuart Mills' 'On Liberty'.

The contemporary philosopher Alasdair MacIntyre, I think wisely, observed recently that there is a fatal flaw within modern moral philosophy. That is that all modern moral philosophers are against all other modern moral philosophers, except the ones who happen to belong to their school of thought and they are not too sure about some of them, either. In other words, I think that to attempt to resolve the matter on the basis of the imposition on the community of notions of autonomy which come directly from a particular philosophical school will not be productive either, because there will be no agreement.

I am saying that we will find no agreement on the basis of the religious/nonreligious divide; and we will find no agreement on the basis of the philosophical schools. So I do not

think we can then appeal to any of those ideologies as a way out of answering the questions: 'Yes, but how do we deal with the demand in our time in some sections of the community for legal voluntary euthanasia? And do we have any right to forbid it?'

The second point I want to make is that we need to be clear about what we actually mean by euthanasia. I use the definition to make it clear that we are talking about an act, or omission, which intentionally brings about the death of the patient or the person involved. There is frequently a confusion about the distinction between motivation and intention. You see it often in the Dutch writers: 'My intention in giving euthanasia to this patient was to relieve suffering'. That is not an intention at all that is the motivation. Intention is to do an act which brings about a result. So in law, for example if a person is accused of homicide, the police will normally try to find a motive for committing the alleged crime for money, for revenge or whatever as distinct from, and in addition to, seeking to establish whether by the act that they did, they had an intention to do something.

Intention is an integral part of law and morals. It helps us to distinguish acts which look the same, but which are really quite different. I once defended a university student in a court of law who had nicked a chair from a women's college where he went to see his girlfriend. He had probably had more drinks than were good for him. The girl was not there and he thought it would be rather fun to pinch this chair. Unfortunately the head of the college called the police and he was charged with theft with rather important implications since he was a law student. Our defence side was able to show that it was a prank, that there was no intention to permanently deprive the college of the chair. Everything turned upon this question of intention.

I think, therefore, we need to be very careful, when we deal with voluntary euthanasia, that we are talking about acts or omissions with an intention to bring about death. We are not talking about an act where the intention is to kill pain, but which might incidentally shorten life; there is no intention to kill the patient. We need to be clear about the distinction of motivation and intention.

As a matter of public policy, how do we resolve this? What I want to present to you is an argument that says that because I might think something is morally right, it does not follow that I would necessarily want to see it enacted as public policy. I want to present it in the first instance by way of a parallel example.

I think you can make a very good moral case for capital punishment. People will agree and disagree about that, but abstracted from any of the realities of actually doing it, I think you can show that there is a very good case for the state having the right to take life in certain circumstances, for the defence of the common good. However, notwithstanding the fact that I think that, and notwithstanding the fact that on best account usually between 57 and 60% of Australians at different times are in favour of capital punishment, I am opposed to it as a matter of public policy. It can never be safely implemented because the people who will implement it are fallible human beings, who may be driven simply by the propensity to make mistakes, or through malice.

In New Zealand, for example, Mr Thomas was put in jail for murder and he was there for 10 years. It was later discovered that the evidence had been planted on his property by the police, causing him to be released and compensation paid. In the state of South Australia very recently, in the last 10 years or so, Mr Splatt went to jail for the killing of a woman. The inquiry showed that although he had been in jail for 6 years, he did not kill her. And of course there is the Lindy Chamberlain episode, where forensic evidence was again found to be faulty. Nevertheless the woman had spent time in jail. My point is that if any of those people had been executed, it would simply be too late to make any reparation.

One could hold a view that says: 'I personally favour voluntary euthanasia, and I perceive that probably the community out there might even agree with me it might not, too but it does not necessarily follow from that that I will be persuaded that I ought, as a parliamentarian, enact that kind of public policy'.

How, then, do we deal with the matter from a public policy point of view? What points of reference are there for us to help decide what is in the common good? I take the view that there are certain fundamental, agreed human values which transcend religious and philosophical differences. These can be found, for example, in the Universal Declaration of Human Rights, which meets the requirements of nations across the world, and the various charters or treaties that have emerged from it.

There are a number of rights here, of which the right to life obviously is one. The right to freedom is another. They are held by these charters to be both inviolable and inalienable. Obviously inviolable means not to violate, but the inalienability question is really very fundamental. An inalienable right is a right of which I cannot be deprived by the state, and of which I cannot even deprive myself. That has clear implications for euthanasia.

Why may I not deprive myself of these inviolable rights? Because if I am allowed to, it threatens the rights of others. Take, for example, slavery. If I say to you: 'I want the right to be able to sell myself voluntarily, and for very compassionate reasons, into slavery. I have become unemployed, and I am too old to get any other kind of job. But I have found somebody who will buy me. It will secure my wife and children for the future. Will the parliament allow me to do that?' The answer is no, the parliament will not. The parliament knows that to do that is to legalise slavery, and that others will be drawn into the slave trade far less voluntarily than John Fleming. Therefore it would represent a threat to the freedom of other members of the community. Since the parliament has to have regard to the common good of all citizens even if it might be a morally right thing to do, to sell yourself into slavery, or at least arguably so, or a matter of opinion or choice can the state set up the sets of circumstances in which it could be pursued?

It is the same with the right to life. The notion of inalienability goes back to the 17th century, to the philosopher Thomas Hobbes, who is really the father of the contemporary human rights movement. His stuff influenced, for example, the Rights of Man in the French Revolution, and of course the various charters of rights in the American Revolution. In this century it led to the League of Nations and ultimately the United Nations.

Hobbes' notion was to consider what human beings were like in a state of nature, where there was no government. Remember that Hobbes was an utter sceptic. He said the only thing that stands up, when you give scepticism its full blast, is that human beings want to survive. They will do anything and everything that is necessary to survive. That will even mean that they claim the right to kill other people, to look after themselves and their own, and will do so. Remember that Hobbes was writing in a time of civil war in England. It was pretty much the case that there was no settled government. He referred also to certain times in American history, contemporaneously. Of course, in our own day we would probably look at what used to be called Yugoslavia.

Hobbes' thing is that reason teaches us that we cannot live like that. If we allowed that to go on, we would live constantly in the fear of death. The lot of man, he says, is nasty and poor, brutish and short I think you know the quote. So, he says, what happens is that human beings contract with each other and with the Leviathan the government, parliament, king, whatever and the deal is this: 'I will give up my rights to do everything I need to do to survive if you give up yours, and we give them up to the state'.

The role of the state is to protect the security of each individual, to protect us from each other and to protect us from external threat. The role of the state is to set up the set of circumstances where individuals can flourish by having a settled economy, which you cannot have if everybody is at one another's throats. This secular notion of the social contract is at the heart of really contemporary human rights notions. It encapsulates certain fundamental values which, for a peaceable society, have always and everywhere to be protected by the parliamentary authorities.

Do we have any empirical evidence to support Hobbes' philosophical insight, that if I give up my right to life, it will threaten the right to life of others? Or, if I give up my right to freedom, it will threaten the freedom of others? I think that we have two pieces of evidence, which I want to put very briefly to you.

The first is the evidence from the Netherlands. Euthanasia under statutory law there is illegal. But it is in fact legal because of a judgemade law. Effectively what it means is that if a doctor does an act of euthanasia following the strict guidelines set down by the courts, he will not be punished. The Dutch authorities hold that these strict guidelines must be followed. The Dutch, as you know, did a survey of what was going on, a prospective survey, and we have the Remmelink report. One of the difficulties of handling the evidence in that report is that the definition of euthanasia is different in Holland from other jurisdictions. When they use the word euthanasia, they mean what you and I would call voluntary euthanasia. So when you see, 'euthanasia, 2300 cases', it does not include nonvoluntary euthanasia.

Using the definition that I proposed at the beginning that is, the bringing about the death of the patient, by act or by omission, only when there is an intention to do so I then went through the report, as many other scholars have done, to discover the categories which would fit that description. There were many more than the 2300. One category, for example, simply had 1000 cases where the patient's permission was not sought but the patient was euthanised. There were many other such categories.

Using the most conservative reading of that evidence, there were 10 500 such cases, in the year 1990 in Holland, where there was an explicit intention to bring about the death of the patient. 'Explicit' is the word they use. There are a whole lot of others where there was an implicit intention. I will stick for the moment with the explicit ones. It set down those who were euthanised by request, and those who were euthanised without request. 55% of the cases of euthanasia that is, the intentional bringing about of the death of a patient by act or by neglect were nonvoluntary. I say nonvoluntary, rather than involuntary, because involuntary means against the will of the patient. I have no way of knowing whether that was true. So I simply use the lesser terminology, nonvoluntary, as a kind of a catchall. It means simply that their consent was not sought and not given. It was not sought, but euthanasia took place.

The second piece of evidence, interestingly, is in South Australia, where a piece of research was carried out by Christine Stevens and Riaz Hassan from the sociology department of Flinders University, pursuant to a request by a select committee of the lower house. Christine Stephens, the prime one who did this research, had no interest in euthanasia and took no view of it. I have had long discussions with her about her research. There was a pot of money sitting there in the sociology department; if it was not used by the right time it would go back to the government, and nobody likes that. In any case the state government wanted a piece of research done. So she accessed the pot of money and went about her work, to look at the practice of doctors and nurses in the state of South Australia in the matter of euthanasia.

The relevant findings, for the purposes of what I want to put to you, are that in this jurisdiction where euthanasia is illegal, because it is governed by the laws of homicide and assisted suicides which prohibit any homicides, 19% of doctors had brought about the death of a patient by active means that is, about 1 in 5. But the interesting thing about this research was that she also asked a further question elsewhere in the survey, on these lines: 'Have you ever had a request from a patient for euthanasia?' She then crosscorrelated the questions and found that of the 19% who had ever taken active steps to bring about the death of a patient, 49% of them had never received a request from a patient that is, in nearly half the cases it was nonvoluntary euthanasia.

I asked her whether she was surprised by this. She said that given the detailed interviews she had with the doctors, on the whole she was not. Of course many of the doctors were very good doctors, but there were also, she thought, some with an extraordinary arrogance. They simply took a view that it was time some people went. Given that they thought it was all right for doctors to do this, they simply, as it were, took the matter into their own hands.

My point about it is this: Hobbes' philosophical insight, that the giving of a group of people in the community the right to take life at the request of the patient threatens the right to life of those who do not request it, is amply brought out by the evidence. This is in fact a more dangerous public policy than the implementation of capital punishment. Even if one personally holds the view that voluntary euthanasia is something one may want, or that one sees no moral harm or nothing wrong with this, or that it is a matter of opinion, it does not follow that one would necessarily think this to be a safe public policy, having regard to the requirement that the parliament is there to protect the common good of all citizens.

---

One of the other matters that I want to draw to your attention, which appears indeed in the bill, is the requirement for prognostication of 12 months to live. That is important because of something that happened just recently in the Netherlands. In 1994 a Supreme Court decision refused to punish a psychiatrist who had supplied a severely depressed woman with a deadly dose of sleeping pills. The woman was depressed because her marriage had come to an end she had been married to a very abusive husband and her only 2 children had been tragically killed. She did not want to go on living.

It had always been one of the necessary rules of the Dutch system, as indeed is proposed by this legislation, that there had to be some terminal phase requirement. The Justice Ministry has now removed the terminal phase requirement and said really all that matters is the sufferer. Apart from the fact that it is a matter of medicine, it is not possible to predict with any degree of certainty that somebody will be dead in 12 months. Precisely because of that, the spokesperson for the Dutch Medical Association said: 'Oh, well, that is not a valid criterion. We therefore have to get rid of terminal phase requirements and simply go to requirements of personal suffering'.

My point is that even with the best will in the world, the difficulty is in being able to set down, in a form of words, a policy which is essentially incapable of being supervised. It is really impossible to set it down in such a way that others are not exposed to the fear of death. It seems to me that is, from the public policy point of view, very important.

There are other problems, I think, with the bill. I asked my colleague Karin Clark, who is a consultant to my institute and a lawyer, to take me through some of the particular elements in the bill. She observed that it was largely based on a proposed voluntary euthanasia bill in Victoria. She says that the major difference is that Victoria's was intended only to apply to selfadministration not with the role of a doctor. She makes the observation that the way the bill is currently worded, the delivery of euthanasia could include virtually any method including, I presume, strangling, shooting, anything really. That in itself raises questions about the necessity for killing to be done in a painless, quick and efficient way. It also raises interesting questions about what would count for a nonnegligent practice of euthanasia in other words, questions of negligence might apply here.

Would clause 4.2, I asked, force a doctor to advise other doctors? Would that mean, for example, a Catholic hospital would have to give over records to another institution? What of the conscience of that institution and those who run it? At the moment, of course, in Holland the Health Ministry wants the licence revocation of doctors who refuse to refer to euthanasing doctors not those who refuse to do it, but who refuse to refer.

**Dr LIM:** Can you read clause 4.2 for us?

**Dr FLEMING:** This is Karen's assessment of the thing. She obviously had an earlier draft, because she has 4.2, and there is only 4 here.

**Dr LIM:** Yes, that was removed.

---

**Dr FLEMING:** Right, that is good. May I ask this question of the committee? The import of clause 11.2 is not clear to me, and I do not think it is clear to Karin. Is the requirement of the death certificate being forwarded as soon as possible to apply if the coroner is not required or forced to investigate? We are not familiar down there with your Coroner's Act. Would it simply become a matter of rote that you handed over the certificate of death, and that really the only role for the coroner is to tot up the numbers at the end of the year? Perhaps it is for you to tell me that that is not the case.

**Dr LIM:** Again, I cannot speak on behalf of the proponent, but I understand that the requirement was more a process, rather than that the coroner will actually investigate each case as it comes through.

**Dr FLEMING:** That raises questions of how one can make the practice of euthanasia accountable, particularly in a practice where 2 doctors both observe the patient. If a doctor believes the euthanasing doctor did not carry out the process, is he going to complain, is he going to make some notification? Moreover the act as it reads to me and again I would be keen to be instructed by you implies that while the second medical practitioner has to confirm the first medical practitioner's opinion as to the likelihood of the patient dying within 12 months, he does not have to testify to the competence of the patient Nor is it clear to me what would count as competence in this bill, and how you would wish it to be assessed. There are a lot of questions about that which I think really do need some teasing out and some thinking about. Again, I am not sure that it is possible to do that in law, but it is something that has to be thought about.

What are the reasonable grounds, to which the bill refers, to account for competence? As I say, the second doctor does not have to certify competence. The requirement that the medical practitioners inform the patient of the nature of the illness and its likely course and the medical treatment, including palliative care, that might be available to the patient again, I think it has to be checked. Among any group of human beings there are the good, the bad and the ugly. A public policy of this kind delivers into the hands of all people in the profession the good, the bad and the ugly the same power, which is the ultimate power that one human being has over another. For these kinds of reasons, wherever euthanasia is practised, we see abuse. I think that as public policy decisionmakers, that is what must really stand out in your minds.

I also draw to your attention an interesting piece of work carried out by the New York State Task Force on Life and Law, reported in the Bulletin of Medical Ethics of August 1994. The Task Force came out unanimously opposed to euthanasia. But the interesting thing is that the members of the committee were divided on the moral rightness or wrongness of euthanasia:

**Some members do not believe that assisted suicide is inherently unethical or incompatible with medical practice. On the contrary, they believe that providing a quick, lessprolonged death for some patients can respect the autonomy of patients and demonstrate care and commitment on the part of physicians or other health-care professionals. Nevertheless, these members have**

concluded that legalising assisted suicide would be unwise and dangerous public policy.

That is in line with what I am saying. Whatever view one takes of the matter personally, we ought to be able to stand back from that. We should perhaps stand back even from some of our own personal experiences, which might seem emotionally compelling. We should be able to ask: 'From the point of view of the safety of the community, is this something that we ought to be doing?'

Mr Chairman, I think that is probably enough from me at the moment. I have with me some copies of particular papers. I brought the New York thing, and the various work by Karin Clark. I brought the AP news report of what is going on in the Netherlands. That is our typedup version, but I have an original here to show you that it is one and the same it is just easier to read.

**Mr POOLE:** They are available so we can copy them?

**Dr FLEMING:** Anything like that, I am very happy for you to have. And there is a paper which I took the liberty last night of giving to Richard Lim. It is a more scholarly setting down of what I put. He tells me it is a bit hard to get into, for which I am sorry. I presented it in the form that I have today for ease of [inaudible].

**Mr POOLE:** Thank you. Just to pick up on a point you made with regard to competence, I note that in the back, in the declaration by witnesses, the second practitioner does actually have to agree.

**Dr FLEMING** Oh, really?

**Mr POOLE** Yes, it says: 'I am satisfied that he or she is competent and his or her decision to end his or her life has been made completely voluntarily and after due consideration'. But I take your point re the actual competence.

**Dr FLEMING:** What that means, yes. Thank you. May I have a copy of this latest ...?

**Dr LIM:** I find that people frequently compare the Netherlands experience with what we wish to do. Do you see any significance in the cultural difference between Dutch people and Australians? We have quite a different culture and quite a different attitude towards life and living, compared with the Dutch ethic. Perhaps the Remmelink report and the Netherlands experience may really not be relevant to Australians and the Northern Territory.

**Dr FLEMING:** I have been to the Netherlands almost every year, I suppose, for many years. My late colleague was Dutch; I stayed in his relatives' homes. I have very close contacts with institutes in Maastricht and in Ede, and I wish I could answer the question. I have actually put that question to the Dutch themselves. They kind of shrug their shoulders and say: 'Oh, no, we do not think we are that different. But there is our tradition of a liberal society. We were a dissenting society, hence the Dutch Reformed Church and so on. But that

should not be any different to anywhere else'.

---

A Dutch doctor told me that there was some suspicion on the part his colleagues about using morphine, because a few of their patients would become addicted. So palliative care was not practised in the way that it would be practised in many parts of Australia, and therefore patients were left suffering, or with unrecognised or untreated depression, which is an important question. I worry about this bill giving enough time for that to be dealt with, too. The timeframes with which we are dealing in the bill are very short. I have heard that said in Holland.

Do I think it is any different? I know that the Dutch were meant to provide the head of the European Medical Association, on rotation, and missed out on their rota because the other medical associations would not buy their practice. I know that they approached the World Medical Association for its approval of the practise of voluntary euthanasia. Delegates to Madrid in 1987 found the opposite.

I am not persuaded that they are different. I love the Dutch and I find myself very much perhaps because I am English in harmony with their very pragmatic approach to life. I think it is relevant. I think their situation is relevant in many respects, and I think we would be wrong not to listen to the Dutch and not to learn from their experience. That is the best answer I could give you, but it is very difficult to work out cultural differences between people.

**Dr LIM:** Yes, I see that cultural expectations may be different. What happens in Holland will not necessarily happen in the Northern Territory or Australia; it is not transportable in that sense.. They may slide down a slippery slope easily, whereas in Australia we might not do that. Sliding down a slippery slope is really a matter of conjecture in some senses. If you take away their cultural differences, the Dutch people the Boer War and all that, the Dutch mentality I do not want to be racist. They are a different group of people. We are Australian, and we think differently.

**Dr FLEMING:** I can respond to that. The reason I chose to bring to your attention the South Australian experience was to show that in fact there was a similarity of eventuality wherever euthanasia is practised one in a society where it is legally tolerated and the other where it is not. Secondly, I think we need to handle slippery slopes very, very carefully. Some will ask: 'How can you know there is a slippery slope? Euthanasia was illegal in Holland prior to the 1970s. We have no idea of or feel for the numbers. Therefore we cannot say there has been a slippery slope'.

I am certainly not arguing that there is, because there is a problem with that. I am using 'slippery slope' in a very confined frame of reference, within euthanasia itself. I am simply saying that if you have a practice of voluntary euthanasia, it will slip across to nonvoluntary there is where the slope is. Not that you necessarily will have more, though I think we will. I cannot prove that we will have more after than before. My statement is that wherever voluntary euthanasia is practised, it will slide over to nonvoluntary, because you cannot quarantine the one from the other.

---

In the end, people become confused themselves as to which category they are really in, and whose needs they are meeting. Are they meeting the needs of the relatives of the patient to die? Is the patient asking to die because the patient has been made to feel that they are a burden , or if not made to feel, suspect they might be a burden? They do not necessarily particularly want to go at this moment, but as an act of altruism.

And of course there is this question of trusting doctors, of speaking to a doctor. I saw a report of Channel 9's most recently released AGBMcNair report, which showed that doctors, who were top of the trusted professions for decades, unfortunately had slipped to No 6. I do think that as a matter of public policy, we must ensure that people go to their doctors when they are ill and not be afraid to go. Anything that we do, I think, must always be done with the common good of the sustenance of the health of the community. It would be tragic if people did not go to their doctors in time, with a suspected cancer or something, because they were afraid of their doctor or felt they could not ultimately trust the doctor.

**Mr POOLE:** Doctor, if we picked up your comments and ended up with a list I am sure it would be quite easy to do, going through the transcript of, for want of a better term, the dangerous areas as you see them, and as a committee we attended to and ticked off all the various things that concern you, at the end of the day your stand would still be: 'No, do not do it, because despite all that it is a moral question'.

**Dr FLEMING:** No, it is not my position absolutely not. My position would be that the one thing you cannot answer in a document like this is human nature. I am directing your attention to the realities of what we are like. I am saying that no matter how well you construct any law, the ingenuity of human beings at some later date will find a way around it. I am putting to you that if, in the state of South Australia, where we know that 19% of doctors practise euthanasia, given that it is illegal and homicide is a very serious matter, there are heavy punishments there why do we imagine they would be any more lawabiding if you legalised it? So I am directing your attention to human nature. I do not agree with homosexuality, yet I am in favour of decriminalisation. From a public policy point of view, I do not think it is right to think that everything that you might as an individual regard as a sin should be a crime. We would not have enough jails to put adulterers in, for a start. I think adultery is wrong, but I am not arguing that it be criminalised.

My point is that this is such a fundamental human value, which we are committed in international law to protect and defend, which for the common good we have to protect. We would be naive to imagine that we could ever have such a public policy where you give the ultimate power that one human being can have over another, and there not be abuse. That seems to me to be fanciful.

**Mrs BRAHAM:** You have already stated that it is being practised quite openly in South Australia, and I guess in every other state of Australia, and that it is actually being done illegally. Would we be naive to say that by closing our eyes and not making it legal, it will go away? Because obviously it will not go away, it will continue. Who is not to say that it will increase, and perhaps because it is illegal, it will be abused even more? Whereas to have a law

that actually puts down steps and safeguards, then perhaps it can be more controlled. At the moment it is happening in an unsupervised manner.

**Dr FLEMING:** It is a very fair question, and I appreciate it. Let me say it is not practised openly in South Australia at all; it is practised, by its very nature, covertly. There are two things I want to say about it. First of all, I think the Dutch experience shows us that to make it legal does not mean the abuses will go away quite the contrary. Secondly, I think in almost every area where there is behaviour practised in the community which is against the common good and we have laws against it like theft, thieving still goes on we nevertheless do not say: 'Because people steal, which they most assuredly do, or commit frauds, we are not going to punish them. We are going to provide disincentives for people who do this'. It does not follow that because something is done illegally, we should make it legal. And it certainly does not follow that if we make it legal we will be better able to control it. The evidence I have seen suggests to me that we cannot control it. I think that is just the reality.

**Mr POOLE:** It is interesting when you look at the current position of governments around Australia on the decriminalisation of marijuana, is it not?

**Dr FLEMING:** Can you just say a bit more?

**Mr POOLE:** I am just taking your comments in the perspective of things happening illegally, and there is this push around Australia to legalise the smoking of marijuana.

**Dr FLEMING:** Yes, but the abuse is still there. Even in our jurisdiction, in South Australia, where there are socalled onthespot fines and a certain amount allowed for personal use, we have seen an explosion of marijuana pushing. And of course, as you know, the marijuana being grown now is far more potent than it was when the '60s people were around.

**Mr STIRLING:** John, given your fairly recent experience in the Netherlands and your visits there, in the wake of the Remmelink report, which I guess horrorstruck a lot of people, is there a backlash occurring? If not, why are people not up in arms saying: 'Let us do away with these judgemade regulations, because they are out of control'?

**Dr FLEMING:** Again, a very good question. The fact of the matter is the Dutch report is written in such a way as to play down the incidence of euthanasia. Some Dutch critics, after first praising the Remmelink report, accused the authors of deliberately putting under dissimilar headings things which were really the same, in order to keep the numbers low.

The authors of the Remmelink report remain very strongly committed to the public policy of legal euthanasia; there is no question. However, in the jurisdiction across the water, in the United Kingdom, there is no doubt that the Dutch evidence had precisely the effect that you mentioned. The select committee on medical ethics of the House of Lords very much had regard to that. I know of people on that committee who are strongly personally supportive of euthanasia, but nevertheless said: 'Really, we do not see this as a policy that could be

12

---

presented safely to the community. We would like to be able to do so, and we would like to be able to leave it as a matter of choice, so that those who wanted it could have it and those who did not, did not have to have it. But we are better off continuing to pursue a good standard of palliative care, and all those other things that are necessary to help a patient die well'. So it has had an impact there. It had an impact in South Australia, where voluntary euthanasia was rejected. You can read that from the reports. I gave evidence at that committee, drawing attention precisely to this kind of material, as did many, many others. In other jurisdictions, as in Holland, it really has not. It is a very interesting thing.

**Mr STIRLING:** Christine Stevens' work in South Australia when did she do that?

**Dr FLEMING:** 1991. There is a copy here if anybody wants to look it. That one is available, the one on nurses. The New York one I can give you. Did you want the AP report? That is an interesting thing, too, from Jochemsen, from Ede, 'Euthanasia in Holland: an Ethical Critique', which you also may find helpful. And there is my own paper here, 'Euthanasia, Human Rights and Inalienability'. Would you like a copy of that document?

**Mr STIRLING:** I do not pay high regard to newspaper editorials in the Northern Territory, but a recent one mentioned other jurisdictions in which euthanasia was practised. I am only aware of the Netherlands and the Oregon legislation, which I believe is being challenged in the court. There is nowhere else?

**Dr FLEMING:** The fact is that the Netherlands is the only jurisdiction we have to go on certainly the only one with that kind of detailed data except for the South Australian study, which I think, when you read it, you will agree is a very thorough piece of work. It has not drawn any critique as to methodology, so it gives us a very good picture of what is going on in South Australia, illegally. But you are right; Oregon is tied up in the courts.

Could I just make a comment about opinion polls, incidentally? They are notoriously unreliable. There were 4 constitutional amendments, I think, before the people of Australia in the '80s. Public opinion polls were running something like 80 to 85% in favour, but the people voted 85% against, on the day. In Washington State, 55% of people polled were in favour of voluntary euthanasia but voted against it when given a referendum, and the same thing applied in California.

What opinion polls do not measure is, first of all, what people know about the subject. Secondly, the word euthanasia is used in so many different ways that people are unclear as to its exact scope. Thirdly it is one thing for people to say they are in favour, and another for them to consider the consequences of passing a law. I think that probably accounts for why there are often discrepancies between the way polls appear to go and what people in the end, upon mature reflection, might decide is the prudent way to go.

**Mrs BRAHAM:** You talked about human rights and people's rights to decide. One of the arguments we hear quite often is that this bill will actually give people the right to choose whether they want to have euthanasia or not. It is a choice thing, whereas if we do not have it, 13

---

you have no choice. At the moment, as you say, it is being practised illegally sometimes without people even being consulted. Do you think this philosophical argument of having the right of choice within our society, which we have in many other areas, is a valid one?

**Dr FLEMING:** It is central to the utilitarian philosophy. Mill said among other things: 'Over my own body I am sovereign'. That is just a statement of faith on his part. It is not true in many other areas of society. We require people to do things to their body, or not do things to their body. We simply say: 'That is a choice you are not allowed to have'. Why? because of the common good.

Whenever complex socio-moral and socio-legal subjects like euthanasia are concerned, beware, I think, of choosing one single principle as the means to resolve it. It is a free choice that is neat. But the truth is, we would not apply it anywhere else. There are other factors which make up the common good as well, interests which the community has that it wants to defend. As I say, there are many other things in life that I am certainly not allowed to choose to do. I do not think that is a sufficient argument.

In this area there are choices about the way you die. Many of those are very worthwhile: the right to refuse unwanted treatment futile, burdensome, disproportionate to benefit the right to access or not access, if I do not want to, adequate painrelief treatment, the right to die at home if at all possible, and so on. There are many, many ways in the dying process that people can choose things that suit them and their families.

One of those choices could be voluntary euthanasia; the question is, is this a choice that we think would serve the common good? And I do draw your attention back to the notion of the common good which is at the heart of the Universal Declaration of Human Rights, as is the whole notion of inalienability. If one wants to make a kind of a free choice, to have faith in John Stuart Mill, why not have a free choice to have faith in Catholicism? Islam? Buddhism? Kant? Aristotle? Aquinus? It is just picking a philosopher.

I know that some are quite addicted to utilitarianism, but it is a philosophy which has been subject to devastating critique. There is no agreement on it. It is highly problematic because, as I say, there are those who have faith in it, but it is a faith position. It is not a faith that I would be prepared to recommend, because there are holes in utilitarianism which you could drive a truck through.

**Mr POOLE:** Anything further? All right, doctor, thank you very much for your time. It was very informative and thoughtprovoking, I guess.

**Dr FLEMING:** I have enjoyed it, thank you.

**Mr POOLE:** Hopefully we will not need to come back to you. But if we do, obviously we would appreciate your making yourself available.

**Dr FLEMING:** I would be very happy to.

---

**Mr POOLE:** We will send you a copy of the transcript. Obviously if there is anything there that you feel you want to amplify or maybe gives a false impression, you will have the opportunity of correcting your own transcript.

**Dr FLEMING:** Thank you. It is amazing, sometimes, you say things in a way that makes you later think: 'Hell, why did I say it like that?'

**Dr LIM:** You said we could have a copy of your legal opinion. Unless it is confidential, it might be useful to have a look at how another lawyer looks at the draft.

**Dr FLEMING:** Sure, I do not think Karen would mind. It is a personal letter to me, so perhaps I had better clear that with Karen that is very fair. Perhaps the various sections ... If I hand that over to you, Mr Chairman, in due course, would that be ... She did it to assist me, but I do not have her permission to do that. My own stuff is mine, but ...

**Mr POOLE:** All right, thanks very much.

select COMMITTEE **ON EUTHANASIA**

HEA**RING**

Monday 20 March 1995

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr Helga Kuhse, Director, Centre for Human Bioethics, Monash University

**Note:** This is an edited transcript.

**Issued: Tuesday 11th April 1995**

---

**Mr POOLE:** I declare open this meeting of the Select Committee on Euthanasia on 20 March 1995 at 9.10 am. Present are myself, Eric Poole, as chairman, Lorraine Braham, Syd Stirling and Richard Lim, and Caroline Coleman is taking the minutes for us. I welcome our guest today. Please state your name and the capacity in which you appear in front of the committee.

**Dr KUHSE:**. My name is Helga Kuhse, and I appear in my capacity as director of the Centre for Human Bioethics.

**Mr POOLE:** Thank you for finding the time to come and talk to us. What we would like to do is give you the opportunity to say whatever you would like to say. Then, when you have concluded your remarks, we can go into a general questionandanswer session.

**Dr KUHSE:** Would you like me to make a formal presentation of some sort?

**Mr POOLE:** If you would like to, yes.

**Dr KUHSE:** I see you have a whiteboard. If later on I could have a pen, that would be helpful. I have prepared a formal, written submission, but in the morning of my coming here when I wanted to photocopy it, there were problems. I have my own copy here, but I have not been able to photocopy all the attachments.

**Mr POOLE:** We can photocopy it for you.

**Dr KUHSE:** No, I have a large file arranged for you. I will send it within the next 3 or 4 days. I will give you a skeletal outline of my views and my arguments now, and will then formally present a slightly longer version in writing. I should perhaps also say, at the beginning, that the arguments about voluntary euthanasia have been occurring for 20 years, and there is an absolutely enormous literature on the subject. I should also point out that the arguments are very complex sometimes, and that there is a lot of confusion. That confusion is sometimes exploited by proponents less so and by opponents of voluntary euthanasia. I will come to that later.

I am here as somebody who, for philosophical, moral and publicpolicy reasons, supports voluntary euthanasia. This is not a decision which I arrived at overnight. I have been working in this area since 1981. Before that I had started writing my PhD on the topic, 'The Sanctity-of-Life-Doctrine in Medicine: A Critique'.

Perhaps it is helpful to the committee to know how I came to the whole subject. I initially studied politics as an undergraduate, and then worked for 1 year for the dean of medicine. This was in 1979. We discussed bioethics in general, in which I had already taken an interest. Apart from politics, I also studied some philosophy subjects where this was being discussed. One interesting thing that emerged was that medical students in those days did not have any education in medical ethics none whatsoever. That seemed to me extraordinary,

knowing about many of the ethical issues and how difficult it was to deal with them. We discussed questions of allowing to die and of helping to die. My slight involvement in medicine in 1979 further kindled my interest, and I decided to write a philosophical thesis on the distinction between killing, to put it bluntly, and allowing to die, because that is how the debate is normally put.

In medicine we have a longestablished practice that there are times when a patient should not be kept alive, but should be allowed to die. There is also an established practice that if a patient is suffering, then adequate pain and symptom control should be administered, even though it is foreseen and sometimes expected and hoped that the patient will die. There is also a tradition which says that a patient must never be actively helped to die that is, by administering a lethal drug. I will come to that again later, because here it becomes rather complicated.

In one sense, if you administer life-shortening pain and symptom control, then in a way that is a lethal drug, if you know and expect that the patient will die. So when we are talking about lethal drugs, we are talking about non-therapeutic drugs, such as potassium chloride. If you use something like morphine, you might achieve the same outcome, namely that your patient is dead, except that you would ordinarily not call this killing. You would call this adequate pain and symptom control, foreseeing that the patient would die. So the debate is rather complex.

This is what I investigated in my first book, which is much more thorough and abstract in many ways than, for example, 'Should the Baby Live?', which I wrote subsequently or at the same time, actually together with Peter Singer. I know that the committee has been recommended to read 'Should the Baby Live?', and I certainly do not want to discourage you from reading it if you are so inclined, but I would also like to voice caution when you read it, because it deals with the treatment of the severely handicapped at the point of birth. It is not of relevance to your inquiry, which deals with nowcompetent patients, adults, who want to die. The only issue in this book that is relevant to your current inquiry is a short chapter on the debate between killing and allowing to die.

If anybody is really interested in that, he or she should read 'The Sanctity-of-Life-Doctrine in Medicine', because it does not focus on infants but rather on the distinction itself. This book was published by Oxford University Press and should be available in your libraries. I should add that I have also written numerous articles on this debate.

The other book lying on your table, 'Willing to Listen, Wanting to Die', deliberately moves away from the philosophical mode. By the time I edited that, I was involved in voluntary euthanasia, not just as a philosopher. Initially I simply asked: 'Does it make good sense that we draw this distinction between killing and allowing to die?' Later I came to the conclusion: 'No, philosophically speaking it doesn't make a difference, but practically speaking it makes a lot of difference sometimes'. There was a brother who died, a friend who died and numerous people who died in horrible circumstances that I knew about. I thought: 'Enough of the philosophical discussions we need to focus on real people, people living here

---

and now'. Because I happen to live in Australia, this is the appropriate pulpit. This book deals with accounts of people, not all of them terminally ill as defined by your proposed legislation, but at least incurably ill, who want to die. In some cases they experience pain, but in most of those cases it is a loss of dignity as understood by them. There is, for example, one very tragic case, very vividly described, where a person has been diagnosed as suffering from a brain tumour. This person knows that in a matter of weeks or months he will lose all the capacities that once made his life worthwhile, namely his mental functions. He was from Sydney University, a professor of something or other, Rex Mortimer. This impending loss of control enticed him to want to opt out before it happened. His condition was inoperable, so he was terminally ill in that sense. His mental faculties began to wane he could see it and he said to his wife: 'Look, now is the time'.

In this case the woman goes to her doctor and he says she should give 50 of this or 50 of that to her husband. The woman goes home, administers the tablets to the husband . But the husband does not die. Next morning he sits up and is horrified that he is still alive. It has to be tried again. There are other, more gruelling, accounts of people having administered drugs to another dying person, at their request, and then finding that the person did not die. Then they use a pillow or something, and it haunts them for the rest of their days.

The issue in this book is really practicalities. We know from surveys, and they will be attached to your file, that roughly every third doctor in Australia has practised euthanasia at least once. Before the law, these doctors are committing murder, nothing less. The aim of the book was to show that the practice goes on, and if medical help is not available loving relatives or friends will take the action into their own hands, and they will do so because they think this is required of them in a loving or caring relationship.

I wanted to demonstrate in a very practical sense not philosophically speaking what comes out of the law's refusal to listen. Hence the title, 'Willing to Listen, Wanting to Die'. That is perhaps most relevant. We can debate the philosophical distinctions between killing and letting die, double effect, intending and foreseeing, which I will do because I have to, because other people will. We can debate it ad infinitum. But ultimately the question that we must ask is, how do we respond to the real plight of these people? It seems to me that we should respond positively, for two reasons. I think an inherent responsibility arises in societies of a liberal and democratic kind, and in a doctor/patient relationship, that we should respect the autonomy of the people concerned. By autonomy I do not mean a very narrow and legalistic notion of autonomy, I mean that kind of conception that we have of ourselves as being the shapers of our own lives, that we have values, we want to be certain persons, we want to lead certain lives, not other lives, and we want to lead these kinds of lives because they express what is important and valuable to us. We are allowed to express that in our daily lives, and yet at the end of our lives we are often denied this, because somebody says we cannot end our life now, we cannot request help, even though there are plenty of doctors who are practising it, and more would be willing to practise it if it were lawful.

---

The second point is that our laws as they now stand may well be regarded as discriminatory. Our present laws allow competent patients and we are always of course talking about competent patients in the context of the legislation before you to refuse any treatment, including lifesustaining treatment. If you are incurably ill, terminally ill, or if you are curably ill, you have the legal right to refuse medical treatment. Because people normally value their lives, they would not refuse lifesustaining treatment lightly. They would do so only for good reasons, namely because they have judged that their life, their conception of the good life, of themselves as persons, is such that they would not want to live this kind of life.

We find that people do, in fact, in the end refuse renal dialysis. They refuse when they suffer from things like motor neurone disease or multiple sclerosis. They will refuse certain treatments such as respiratory assistance, which is necessary to keep them alive. As a direct consequence of a doctor acceding to such a patient's request, the patient will die. The patient will die because we have allowed the patient to make this decision for himself or herself. The patient will, in those circumstances, die as a direct consequence of what the doctor does with the patient's consent. The doctor in other words will often perform an action which the doctor knows will lead to the patient's foreseen, and often intended and wanted, death. People who are totally immobilised by certain diseases do not wish to lead this life, and in that sense want to die. Of course if the disease were not there, the person would not want to die, but it is the kind of life that the person does not want to live.

In that sense the case between refusing of treatment and helping to die is parallel, except that our law does not see it as parallel. Our law says that if you are lucky enough to need medical treatment to keep you alive, we give you the legal right to refuse it, and we give legal immunity to doctors who assist you in those circumstances. Our law also says that if you are unlucky, if you suffer from a disease that does not require treatment, we deny you this right.

It is interesting that in the United States and Canada, cases have been taken to the courts by people who did not require lifesustaining treatment. In Washington state, Judge Barbara Rothstein last year brought down a judgment that the laws of the state are discriminatory because they allow patients to refuse treatment, but do not allow them to seek active help in dying from a doctor willing to provide it. She says they are discriminatory because, before the law, there is or ought to be no distinction between the two. In the United States context, she said, this law as it stands offends against the 14th amendment to the constitution, which grants every person in the United States an equal opportunity to liberty. Liberty in this sense is being denied those people.

A similar case in Canada went to the very highest court at the end of 1993. This was the case of Sue Rodriguez. She had motor neurone disease and wanted to be able to request assisted suicide from a doctor. Not right away she was told she would probably live another year or two. At this stage she was largely immobile but she could still talk, with difficulty. She said: 'I do not wish to die now, my life is still valuable, I can still interact in some sort of way with my family. But when the time comes that I can no longer do this, this is when I would like the right. I do not wish to be forced to take my life now. I could take it now, myself. I could still swallow the pills. But when I want to die, I will no longer be able to reach out for the pills. I will not even be able to swallow, or breathe properly'.

5

---

I think in the Northern Territory you have a criminal law which prohibits one from committing suicide. You are the last territory or state that still criminalises suicide. That seems very anachronistic. In the Middle Ages they used to punish offenders by putting them to death. But in that sense you could argue that you are more consistent. In Canada and the United States and in Victoria, for example, it is no longer a crime to take your own life. You are at liberty, if you want to, to take your own life. In our states it is a crime only if you get assistance. This was the argument of Sue Rodriguez. She said: 'Ablebodied persons can take their own life, that is not a crime. But the law prevents a handicapped person from taking her own life and from getting the assistance that an ablebodied person does not need. In a sense it is like not providing the ramp that allows a wheelchair up into a building you are denying access'. But in the Northern Territory it does not apply because in your case even to take one's life is a crime.

**Mrs BRAHAM:** I believed we had decriminalised suicide.

**Mr POOLE:** No, I do not think so. I am not sure.

**Dr KUHSE:** I thought you had too, but I read, just over the weekend, that you had not. My argument, in a nutshell, is that to deny people the right to request help from a doctor willing to provide it, is denying them the right to make decisions about their lives. It does so for unjustified reasons, because it draws a distinction between refusal of treatment which may involve an action, if it is actively turning something off, removing a drip or whatever, and seeking extra help in dying.

That would be my argument for. There are arguments against, of course. In a way I think I am stating the obvious, but seeing that I am asked to make this presentation, I do so. The argument for is about the value of autonomy and about discrimination. There are two kinds of arguments against. One rests on the intrinsic wrongness of killing, whatever killing is we need to define it. I am going to define euthanasia and killing in a minute, but let us take it on face value.

There is a belief that killing is always wrong whereas allowing to die is not wrong, or not always wrong. There is a moral belief that there is a distinction between the two, and it is an intrinsic distinction. Irrespective of the outcomes, that is how it is.

Killing is wrong and allowing to die is not always wrong. In other words, to kill a patient by administering a lethal, non-therapeutic drug, is wrong. To bring about the same consequence, of having a dead patient, by turning off life support is not wrong. That is a fundamental moral belief. I do not share this belief, but there are many people in our society who hold this belief, that it. is intrinsically wrong to "kill", but not always intrinsically wrong to "allow to die".

In the end one cannot argue about it, because these views are based on deep philosophical value judgments. In the case of killing, where this is regarded as intrinsically and of itself wrong, that belief is often also based on religion, because there is a commandment in the JudaeoChristian culture which says: 'Thou shalt not kill'. There is no equal commandment which says: 'Thou shalt not let die'. That is one basis for this distinction. I think we ought to accept that there are those different values, and respect them. This goes

---

together with the principle of autonomy. But to the extent that I will not be able to convince a staunch Roman Catholic that he or she is mistaken in thinking that there is such a distinction, this very same person will not be able to convince me that there is such a distinction. I just do not share this view.

If all other things are equal, if I act for reasons of respecting a patient's autonomy, if I act for reasons of wanting to relieve suffering, it does not matter in my view whether I bring about this consequence by injecting a drug or by turning off a respirator. It does not matter to me, morally speaking, from my point of view. I do not expect people to share it. But I think, as I respect somebody else's view, so my view ought to be respected as well.

This raises the question of public policy. How ought legislators, in a society that respects liberal, democratic values that are based on pluralism, respond to this plurality of values? Should you run with the view which says: 'No, actively helping to die is out, but allowing to die is in', or should you run with my view? I think the view that you should run with is the view that can be supported by the principle of autonomy itself. That leads one to a non-restrictive practice, because a non-restrictive practice would allow those people with whom I disagree, who think it is wrong, to live by their rules, to live by their deeply held values and beliefs, and to inculcate those beliefs in their children. It would give freedom, liberty. On the other hand, a non-restrictive law would allow doctors and patients to choose, from a range of options, that option which best meets the needs of the dying patient. In some cases it will be palliative care only, in others it will be refusal or withdrawal of treatment, and in others it may be assisted suicide or voluntary euthanasia.

A non-restrictive approach is, in my view, the only one that a pluralist, liberal public policy can support. The traditional approach, which outlaws it, incorporates a particular moral point of view that allowing to die is okay, but helping to die is wrong. The Australian population, as you know, does not share this view any more.. Doctors do not, in the majority of cases, share this view. 78% of Victorian nurses want the law changed. I think this is a very large figure. Why do they want the law changed? Because they are by the bedside, they are the ones who are treating terminally ill patients. Doctors will often walk away because that is their role to walk in, to diagnose, and make decisions in the light of the evidence presented by the nurses. The nurses are by the bedside. They know that the patient is suffering and wants to die. This is how I explain the difference between some 60% of doctors wanting law reform and some 75% of nurses wanting law reform. These are pretty convincing figures, in my view, about what the public policy approach on the face of it ought to be.

One powerful argument might be put against all this. It is also an accepted traditional moral and public policy principle that liberty should be granted unless it leads to harm to others. If there is harm to others, there would be strong reasons against implementing such a policy. But it is not just harm to others, it is more harm to others than would result if the current policy remained in place in any particular situation. Public policy is concerned with the overall good and benefits for society. So should we bring in euthanasia from this wider perspective? We should bring it in if it does more good than harm, we should not bring it in if it there is more harm than good coming from it.

---

How do we know what will happen? We do not quite know what will happen. But I think that whatever steps we take, we must always look at voluntary euthanasia in the wider context, where we already have two other endoflife decisions by which death can be hastened by doctors namely the withdrawal of treatment and adequate pain and symptom control. We must look at it in the total context of medical endoflife decisions.

This book, 'Willing to Listen, Wanting to Die', is the tip of the iceberg, of course. We know that there is considerable suffering now by patients being denied the right to seek direct assistance in dying. It is a harm in terms of suffering to those patients and their loved ones. It is also a harm in terms of thwarting, as it were, the liberty of these people to do what they very much crave to do in those circumstances. This is actual harm, existing now. If you ask why there is such increasing support for voluntary euthanasia, the reason is that this real, existing harm is recognised by the Australian population, it is recognised by the medical profession, and it is recognised by the nursing profession.

Now we come to the so-called slippery slope argument that once we bring in voluntary euthanasia, it will not be able to be contained. It will inevitably lead, so the argument goes, from voluntary to non-voluntary and then even perhaps to involuntary euthanasia. I do not accept that argument, because I think the law is quite capable of drawing boundaries around permissible or impermissible actions. If the law were not able to do this, we should not give patients the right to refuse treatment. We draw boundaries around permissible cases there, in terms of the patient's autonomy and competence. We must have, and hospitals do have, safeguards in place to establish competency. A doctor who feels that a patient who refuses treatment is acting irrationally, is totally incompetent in this particular circumstance to make this decision rationally, will not now act in accordance with it.

My view is that the same safeguards that now apply or should apply they do not always apply to the refusal of treatment and to adequate pain and symptom control should also govern medical endoflife decisions that involve active help in dying. If that is the case, we should have no more fear about voluntary euthanasia leading us into the deep end than we should have now, if we think about it reasonably, about refusal of treatment and those other endoflife decisions. It is irrational, in my view, to single out voluntary euthanasia as the bogeyman. It just does not work like that.

People will point to the Netherlands and its horror chambers, to a large extent replacing Nazi Germany as the bogey. With regard to Nazi Germany, the bogey was that if euthanasia was ever voluntary, it soon led to other euthanasia. But the Nazis never started off with voluntary euthanasia. They started off with non-voluntary euthanasia. It was not based on the patient's autonomy, not based on the right to decide, rather it was based on racial prejudice, on wanting to eliminate those who did not fit the Aryan ideal. Holland, of course, is different. In the Netherlands doctors have practised euthanasia in full view of the law for the last 20 years or so. The claim is that since this was allowed, the Netherlands have slithered down a slippery slope towards a situation where patients are now being killed in droves against their will.

---

In my file, which I shall provide to you, there are figures ranging from a mere 1000 patients being killed against their will to 45,000 per year, which makes it very interesting. Yet, in light of these horrors, 80% of the Dutch people support voluntary euthanasia. The point really is that those different figures are utterly misleading, misunderstood , and they are not always, but I think very often used deliberately to distort the debate. People refer to the socalled Remmelink inquiry. They refer to it in 1 paragraph. This is the writtenup Remmelink report. Anybody who is seriously interested ought to read it. The fundamental difficulty with figures, and interpreting them as they come out of the Netherlands, is related to confusions about how we define euthanasia this I shall do on the board in a minute and how we define killings. It has to do with all sorts of different categories.

The fundamental issue, however, is that let us assume the worst scenario, 45,000 people in the Netherlands are killed each year against their will, let us assume for one minute that it is true you can still not mount a slippery slope argument from this. If euthanasia was brought in 5 or 10 years ago it depends how you want to define it you would need two sets of figures. You would need one set of figures after the practice was brought in, and you would need one set of figures for before the practice was brought in. If you have only one set of figures, you cannot demonstrate a slippery slope, because a slippery slope goes from X to Y. One set of figures tells you nothing, because before euthanasia was quasilegalised in the Netherlands, there may have been 55,000 or 90,000 cases of unjustified killing. We just do not know. So the slippery slope argument just does not work. There is one set of figures in the whole world for this is the only piece of data now available. We do not know what is going on in Australia. Incidentally, together with a colleague from the University of NSW, I have applied for funding to repeat this study in Australia next year. Then we will know.

The next fundamental point is that whatever the Dutch do has limited relevance in a different sociocultural context and to a different law. In the Netherlands voluntary euthanasia has not been legalised. It is totally different.

This is really the end of my presentation. I have arrived, after thinking about these matters for 10 years or more, at the view that there is no justification for retaining our existing laws. I should also say that right around the world, moves are afoot that will, in my view, see assisted suicide, voluntary euthanasia, legalised in many countries within the next 5 years. It is also my considered view that, perhaps a generation from now, people will look back at our times and will think: 'What on earth was going on? Why did they allow two endoflife decisions and not allow the third kind? Why did they allow refusal of treatment, adequate pain and symptom control, but deny people adequate help in dying if that was what they chose, thereby thwarting people's autonomy and inflicting more pain and suffering than was necessary?'

The Northern Territory, of course, would be the first. Assisted suicide, by the way, is lawful in a variety of countries and a number of American states. It is lawful in Switzerland, it is lawful in Germany, although in Germany the medical profession would deregister a doctor who practises it. In Switzerland that is apparently not the case, and doctors do in fact provide assisted suicide. You would be the first to legislate for it. You should not be scared of this,

---

because as I understand it, in 1904 South Australia was the first Australian state to bring in the vote for women. I think New Zealand was before them, but they were certainly among the very first to bring in this law reform, which everybody now applauds. That was to end the disenfranchisement of women, and I think something similar might be said about this, because I think this denial of active help in dying is really fundamentally linked to human dignity and to human rights. A government that decides to overcome this will take a step very much in the right direction, and do something of which future generations will be proud.

That is the end of my formal presentation. Now [indicating whiteboard] can I just do something else?

**Mr POOLE:** Before that, please bear in mind that we are going to try to relay everything you have said to us on to our colleagues.

**Dr KUHSE:** Yes. I have not done this in my formal submission, but I can if you like. I shall repeat it.

What is active voluntary euthanasia? It equals killing, people would say, killing on request. And they would want to add that you do it for the sake of the person. In the case of voluntary euthanasia, you would say that it is for the sake of the person and of course it is voluntary, at the request of the person. Then you might have boundaries around it, like 12 months or 6 months or 2 years or whatever you like. But what I really wanted to ask you and I want to demonstrate it, to show how difficult it is not to get bogged down in this is: What is killing? How do we define it? Can you tell me?

When does a doctor kill a patient? People will initially say, when the doctor performs an action. It is an action. The doctor does something that will lead to the patient's death. What we think of is the prescription of a drug or something like that. So the injection of the drug, that is killing. Because you do something, you inject something, and as a consequence you have a dead patient. That seems, on the face of it, very plausible.

But then, of course, people will say: 'Well, if it is an action, that is fine, but what about turning off a respirator, where you know as well as anybody else that it is just as certain to lead to the patient's death as giving a lethal injection? That is an action. Is that killing, or is it allowing to die? People will say turning off the respirator is not killing, it is allowing to die. Very well. But then you must also realise that all the same conditions apply, that the fears that are raised about voluntary euthanasia must surely be raised about this one as well. It is an action.

So, what is an action? An action is doing something ... That is not good enough. What killing really is, in my view, is this: the doctor initiates a course of events which was not there before, in giving a lethal injection, and as a consequence the patient dies. In allowing to die, as in turning off a respirator, there is a patient here who will die unless there is some medical intervention. Here is the respirator. Hence the course of events is already in place namely, the disease. The patient cannot breathe. Here the doctor turns off the machine, does not give life support, and you have a dead patient. Now, in this case here, the

---

doctor gives a lethal injection. Here the patient would die, let us say, if life support were withdrawn. So there are different ways of bringing death about, or of allowing it to occur. The difference between killing and letting die I think this is the only reasonable understanding is that here, in killing, the doctor initiates the course of events, and in letting die the doctor does not intervene or remove the obstacle to allow death to occur.

**Mr POOLE:** But the intention is the same at any rate, is it not?

**Dr KUHSE:** It might be the same. I shall come to that in a minute, because it is a very good point. In many cases it is the same. From the patient's point of view it is almost always the same, because the patient will say: 'This life is dreadful, it is undignified. I can't go on any longer. Help me to die'. The patient may say: 'Turn off the life support', or, 'Give me something to help me die'. Or the patient may say: 'I'm gravely, gravely fearful of suffocating to death. I do not wish you to turn off my life support [and that has happened]. I wish you to give me something to help me die. I do not wish to die gasping for breath. I do not want to die of the consequences of kidney failure. You and I know that if I get off this kidney machine I will be dead, depending on what I eat, in between 2 days and 7 days. I do not wish to undergo it. It's not nice, and I fear it. So please help me'.

This is the distinction, purely philosophically speaking, between causing death and not intervening in a disease process, either by doing something or doing nothing. But then people, of course, recognise that you can kill by omission as well. If I want the inheritance of my aunt, and she is bed-ridden and needs to take a certain pill every 2 hours, and I am not giving them to her, many people would want to say I killed her if she died as a consequence of what I did. And I think it would be justified to call it that. In a sense, the terminology that you choose is arbitrary.

People in the voluntary euthanasia movement say that where you are not acting for nasty motives but for good motives, where a doctor acts because he or she wants to help the patient, respects the patient's autonomy, if you intend to bring about death, as I did when I did not give Auntie the pill, if the doctor here, when he or she turns off the life support ...

TAPE TURNOVER

'... Help me give me a lethal injection', everybody will say that if the doctor acts on it, the doctor intended death. The doctor wanted the person to die, the patient wanted to die, so this it the intentional termination of life it is killing. Here if the patient says to the doctor: 'For God's sake help me to die this is dreadful', and the doctor says: 'Yes, I can understand it, I accept your wishes, I will help you to die', if the doctor in that circumstance intends death, it is the same. People will still want to call this a killing, because they define [inaudible] traditional Catholic moral theology, killing is not an action, it is not causing, it is the intentional termination of life. If a person, a doctor, intends to cause death, to bring about death, this is defined as killing.

---

If I am confusing you I apologise, but this is just how the debate is. This is how all these figures come out of the Netherlands, because people do double-counting. They call this killing. So if you have 10 000 killings in the Netherlands, it is because refusal and withdrawal of treatment are counted as killing as well. If the doctor says: 'Yes, I intended that, because it was good for the patient', it was killing. It is not my terminology. It is traditional moral terminology as, for example, employed in the Vatican statement on euthanasia, the intentional termination of life.

So far, so good. When do you intend death? People will say that if you give a toxic substance, then you always intend death. Do you intend death when you withdraw treatment? How do you tell? Administering pain and symptom control, you need to give someone so much morphine and a sedative to get the patient out of pain. You know, or expect, that as a consequence of what you do, the patient will die. If you happen to think it would be a good thing for the patient to die, in those circumstances you intend death. If you want and in some sense wish that the patient dies, then you intend death. So again, it is classified as a killing.

But from the outside, the two actions look the same. Here is one doctor, turning off life support, and the patient dies. This doctor says: 'The patient has asked to die, now I am obliged. It is good, I can understand it'. This doctor, according to traditional terminology. And here is another doctor who, let us say, keeps his mind very clearly away from the consequences and says: 'I am only withdrawing life support. I know the patient will die, but I do not really want it'. From the outside, the doctor does exactly the same thing. Yet here it would be that the doctor does not kill, the doctor merely allows to die.

Where does all this happen? In the doctor's head. Ultimately, only the doctor himself or herself can tell you what his or her intentions were. In this Netherlands study, for the first time in history, they asked doctors: 'What did you intend to do when you withdrew life support? What did you intend to do when you gave pain and symptom control that you knew would hasten death?' Lo and behold, half of the doctors said: 'I wanted to relieve pain and I wanted to respect the patient's autonomy, but I also intended the death because it was a good thing.' This counts as killing.

If we were to ask doctors in Australia who withhold or withdraw life support and the like what they intend to do, of course they would say: 'In a sense we intend the death'. This is the complexity of the debate in a nutshell. And this is important for public policy.

If intentions go on in people's heads, if that is where it happens, and if only the agent himself or herself can say: 'When I turned off life support I intended death', this is not a good basis for public policy. And yet because our laws, [inaudible] morality, prohibit the intentional termination of life, this is relevant for the law also. In my view, laws ought to be based on something that is obvious, that is visible.

What is visible in the case of competent patients? Consent is visible. The patient says yes. What you often do not get is [inaudible] the intention, what goes on in the head of the doctor, the doctor is only too oblivious sometimes of asking consent. If you have a moral framework which says you must never intend death, and you say: 'As long as I have a pure

---

mind, I do not do it', it looks like nature taking its course. Nature is allowed to take its course [inaudible] consent is not always forthcoming. In my view consent is the appropriate framework for public policy not intentions and the distinction between killing and letting die ought ultimately to be irrelevant. What is important for public policy is that this is what the patient wants.

There are 3 different ways of bringing death about, and not every one suits every medical context. The appropriate way to proceed, in my view, is for doctors and patients to negotiate that mode of dying that best suits a particular patient in a particular context. This requires decriminalisation. Now I am truly finished with my presentation.

**Mr STIRLING:** Thank you. Can I just correct the record, though? That was referred to me by a colleague, not to the committee as such. I [inaudible] might have had a look at it as well, but it was not referred to the committee [inaudible].

**Mrs BRAHAM:** You gave us figures that seem to contradict figures we already had. You said 60% of doctors and 75% of nurses support euthanasia. Do you have evidence to support that?.

**Dr KUHSE:** Yes, I will attach these surveys to my formal presentation. There are two studies of doctors' attitudes and practices. One was conducted by myself and Peter Singer in 1987 and published in the Medical Journal of Australia in 1988. That asked doctors questions like: 'Have you ever been asked by a patient to hasten death? Are you actually working in an area where you are having contact with terminally ill or incurably ill patients?' If the answers were yes, then another question was: 'Have you ever practised voluntary euthanasia?' Later questions were put of the kind: 'Would you favour law reform? Do you think it is right or wrong, morally speaking? Do you hold religious beliefs? Do you think that patients can ever competently request euthanasia?' That is interesting: 98% of doctors agreed that it could be a competent, rational decision. Doctors seemed to accept that.

That study was initially criticised for being representative of Victoria only. It was repeated last year in New South Wales by Prof. Peter Baume and Emma O'Malley, and again published in the Medical Journal of Australia. The figures turned out to be nearly identical. The outcome was that every third doctor in this study who had been asked to do so had practised euthanasia at least once but often more times, and that 60%, roughly speaking, wanted law reform. The NSW study was an exact copy with one additional question regarding assisted suicide. It found that doctors did not make that much distinction in the end.

The nursing study was different because nurses are not allowed, legally speaking, to prescribe treatment. There we just asked whether nurses had ever been asked to participate in voluntary euthanasia, whether they knew of doctors practising it these kinds of questions. The most significant questions related to whether nurses would want to be involved in the practice if it were lawful, and whether they wanted the law changed. Both of those questions were answered by three out of four nurses in the affirmative. Something like 75% and 78% respectively, from memory, said that they wanted the law changed and that they would be willing to participate with doctors in the practice. That is the evidence available.

---

**Dr LIM:** To take up the slippery slope argument, there appears to be an acceptance that doctors will always act to the benefit of the patient. Doctors are people, and there are bad people. How do you control them?

**Dr KUHSE:** My view of doctors is not as bad as the views some doctors apparently hold of their colleagues. I think doctors on the whole do not need terribly much control. I think there is an accepted tradition in medicine which acts very much as a framework for ordinarily the right decisions being made. Nonetheless I think that, as far as voluntary euthanasia is concerned, the situation is currently such that it is different from medically assisted dying by withholding treatment and by adequate pain and symptom control, because there is no legal framework at all. In Victoria, for example, when it comes to refusal of medical treatment, we have a Refusal of Medical Treatment Act which says something very much like your legislation.

I think it is appropriate that two doctors should witness the relevant certificate, and that the patient is competent. It is a formality which nonetheless is helpful, I think, because doctors should not go around and just turn off life support equipment either. I think it is appropriate that one doctor, in a doctor/patient relationship, arrives at this decision with the patient, and that a second doctor verifies it.

Essentially the frameworks that are adequate to cover refusaloftreatment decisions are also adequate to cover endoflife decisions. I am not fearful that doctors will go down the slippery slope. I do not know why they should become more unscrupulous by actively helping patients to die in other words, by doing a good deed. Now, acting in the context of refusal of treatment, they respect the patient's autonomy, they act to reduce suffering, and it would be the same principle. Acting for the sake of the patient will not send anyone down a slippery slope. On the contrary, sometimes if somebody does not get in the way of something good happening to a person, you think that person acted correctly. It is just like nontreatment, having good happen to the patient: the patient wants to die, the disease kills the patient. Sometimes when we actively do something good that benefits a person, I think in a way we are better persons. I think it ought to bring out the best in doctors. It respects patients' autonomy, respects their suffering, and means acting on it.

I think one often sees it in terms of killing. Opponents of euthanasia always, always, ad nauseam use the word killing, as if use of the word killing could win an argument. There are books entitled, 'Why Doctors Should Not Kill Their Patients'. It sounds awful. Of course doctors should not kill their patients. Proponents of euthanasia, on the other hand, say, 'helping to die'. It sounds better, doesn't it? But really speaking, neither of those terms can settle the debate for us. Of course, if you want to discuss killing in a certain way, voluntary euthanasia is killing, and if you want to define it as helping to die, it is helping to die. What ultimately is important are the underlying principles, and those are respect for autonomy and consent to obtain that.

**Mr POOLE:** I guess a lot of the argument in support of euthanasia relates to the fact that all we are really doing is trying to legalise what is already happening anyway.

---

**Dr KUHSE:** That is true. And in a sense by doing that you provide more safeguards than are available now. You are also removing an intolerable situation. I have talked enough about patients. But it is also doctors. I think it is just not fair, where a doctor is forced sometimes to break the law because he or she feels that they are acting how a good doctor ought to act if there is a patient who is suffering.

I think Brendan Nelson, the President of the AMA, has not merely admitted to providing adequate pain and symptom control. He says: 'I have intentionally terminated a patient's life'. But he also seems to take the view that we should not have a law. I do not understand his argument; neither do lots of other people. Why should doctors be outside the law above the law, if you like? As I have argued publicly, if a doctor breaks the law, currently the doctor commits murder. Unless we take the view that doctors are above the law, they should be hauled before the courts. And if we think that doctors should be allowed to perform voluntary euthansia, then I think we should provide a protective space within which they can perform it, because it is not fair.

**Mr STIRLING:** To the bill itself, what in general terms are your own views of it? Do you see any weaknesses or deficiencies in it? I draw your attention to one particular point, and that is that question of competence. It has been put, I guess, to all of us at different times that on advice of being terminally ill there is a clinical stage of depression, and that there ought to be some assurance that the person is not seeking to die at that point of depression, but is in a completely rational state.

**Dr KUHSE:** People are, of course, sometimes depressed when they have been diagnosed as terminally ill. I think that not everybody who is depressed is incapable of making a decision about him or herself. So it needs to be a certain kind of depression. If I were diagnosed as terminally ill now, I would undoubtedly be depressed, but I think that after a bit of reflection on it, I would nonetheless be able to make decisions about myself. The same kinds of questions are raised when it comes to the refusal of treatment. A person diagnosed as terminally ill could now immediately refuse treatment. So the question of competence that is raised is alreade with us. It is not something new that is introduced with voluntary euthanasia, it is something that doctors already deal with. If a patient is depressed, no doctor will act on refusal of treatment. There are all sorts of mechanisms in place that you can bring into force, the least benign one being to have the patient certified. Then you can act. And it happens. So if somebody with a gangrenous foot or something like that absolutely refuses and this person is already delirious, cannot make a decision, then you act.

Regarding safeguards in that respect, I would hate to bring in a period of 3 or 4 weeks. The people who perhaps most need euthanasia would fall through the net. If you are nearing the end of your life and are suffering terribly, and you have another 3 days to live, and you have a waiting period of 4 weeks or even a fortnight in there, it is bad luck. It is away out of costs and benefits. I think I would leave that question to doctors.

If someone is told they are terminally ill but have another 2 years to live a good life yet they say: 'Kill me now', in my view no responsible doctor would act on that. And no doctor is required, that is the point of the legislation. It is not prescriptive of what doctors must do. It is just liberalising: it gives doctors an opportunity to do things. I think no doctor will do more than he or she would now do. To sum up, (a) the problem is not new it must be dealt with now because of refusal of treatment and (b) it is liberalising and it just does not require doctors to act.

**Mr STIRLING:** It concerns me that we are forced under this to put an enormous amount of trust in doctors. I guess we do anyway, by virtue of the fact that we are patients and we seek the help of professional doctors. But I am drawn to a point which was made in a video the other week, where a doctor said that if a teenage boy who had broken up with his girlfriend was terribly depressed and wanted to die, he would kick him out the door. But if a young person came in who had been a professional ballet dancer but lost her leg in a car accident and wanted to die, he would accept that person's view. That horrifies me. That person would still be able to lead, and ought to be leading, a useful and valuable life. But doctors are human, and influenced by their own background and experience and view of things. This doctor's view horrified me. While we all have to put trust in the medical profession, in this area I am concerned by the amount of trust.

**Dr KUHSE:** True. But this person the ballet dancer would not fall within the confines of your bill. Having lost a leg is not a terminal illness. That would rule both the ballet dancer and the depressed teenager out. I could give you a parallel case where a person needs to have her leg amputated. She says: 'Don't you dare amputate my leg, because I am a ballet dancer and I will never be able to dance again. I want to die now'. It is again the same question.

We must place trust in doctors. By all means try to have the legislation as tight as possible, but don't go overboard. I think it would do more harm than good. It ought always to be seen in the larger context of those other endoflife decisions. You should not try to write very restrictive legislation, because problems will be created that were not here before. I think the best possible way to provide an open space for doctors and patients to negotiate is trust. Without trust nothing works, and the law cannot legislate for trust. I think it would be a mistake to try to draft a piece of legislation that tries to cover too much. I do not know how else to answer it. If a doctor wanted to act on a hasty request, we cannot stop it, law or no law. Doctors [inaudible] too much, I think.

**Mr STIRLING:** No, I agree with you from that point of view. It is a concern, it is not readily tangible, I guess. The more things that you would seek to put in and this applies to any legislation the more [inaudible] to be rounded off at the edges in practice, in order to make it practical to use. The simpler [inaudible] easier and better for everyone to follow.

**Dr KUHSE:** I think I can see why these concerns come up when one has a new piece of legislation before one, and I can see your concerns, because you will be subject to precisely all those criticisms and these will be the cases that will be presented. But I think legislators have to be a little hardnosed and argue the case that trust needs to be there, and that no law can be tight. You cannot rule out unscrupulous doctors, because you do not need a law for

doctors to be able to kill patients unjustifiably. They can do it now. So the only thing this can do is provide protective space within which those decisions will be made more transparent. If it becomes more restrictive and something like the Netherlands, with 38 clauses and subclauses and boxes to tick and documents to fill in, people will not follow it. I think it is more an education process, built on trust. Just by having two doctors to sign the certificate, it is infinitely more than we have now.

**Mr POOLE:** It is a bit like the debates on abortion and marijuana smoking and all those sort of things, whether or not it is better to happen above the surface, declared, or below the surface and people are still doing it.

**Dr KUHSE:** People forget that those problems already exist, that they are not created by the legislation, rather they are there. It is just that they are submerged. We pretend they are not there, and we do not have to face them because we are not trying to write a law about them. Once we try to write a law, all of a sudden they seem to be there. They were there all the time.

**Dr LIM:** The question that was asked first was, are there any weaknesses in the bill that you can see now, that need to be tightened up?

**Dr KUHSE:** I have not really seen any weaknesses. It is a good bill as far as I can judge. I had an extensive look when it first came out and when it was redrafted, and again last night and over the weekend. It seems to me that it is a good piece of legislation. Large parts of it have actually been lifted from the Victorian draft bill, which was drafted by Prof. David Kelly, the former chairman of the Victorian Law Reform Commission. To the extent that these bits conform to the Victorian legislation, I think they are already pretty good. They could not have had a better judge than David Kelly. I was one of the people who worked with him on those clauses. So on the face of it, it seems pretty good.

I have a question regarding one or the other of the clauses, but I think in my own mind I have worked out what it is. There is an open clause which I could not understand, but I think it relates to your having the Natural Death Act. It is 17.3: 'A request by a patient for assistance under this act, or giving of such assistance in good faith by a medical practitioner in compliance with this act, shall not constitute neglect for any purposes of law or alone constitute or indicate a disability for the purposes of an application under section 8 of the Adult Guardianship Act'. I cannot understand this clause, but it is directly related to your Guardianship Act and to your legislation, with which I am not familiar. [Inaudible] effect on construction of wills, relates to your Natural Death Act. Initially I could not make sense of it. That is something for you to judge, how it fits with other, existing legislation.

I would not wish to have many more clauses in there, making it more cumbersome. It is clearly written on the whole, which is another good thing. The Victorian Voluntary Euthanasia Society had a bill drafted by a parliamentary draftsperson initially, and it went to some 20 pages with clauses and subclauses. It would be impossible to administer, impossible for doctors to follow. It would do more harm than good.

17

**Mr STIRLING:** The word 'dignity' is used frequently by both sides in the debate. It is one that confuses me because [inaudible] the right to die with dignity, while the other side I suppose says there is nothing dignified about a lethal injection and [inaudible]. Whatever [inaudible] has that measure of dignity about it. The proponents of euthanasia talk about dying with dignity. Could you just explain that?

**Dr KUHSE:** It a very good point that you bring up. I think the word is confusing, and it is used inconsistently. I probably am guilty of having used it myself this morning. To my mind dignity, in the case of normal adult people, is related to respecting their autonomy. It is not an objective notion that applies to everybody, that dying under certain circumstances is undignified or is dignified. No, it relates to what the person sees as dignified from his or her point of view. If one values mental capacity extensively, like Rex Mortimer in my book, "Willing to ListenWanting do Die" who has lived as he put it always by his brains, and now he should finish up as 'a vegetable', as somebody who is losing the capacity which defined his life and made him the kind of person that he wanted to be, then this is experienced as undignified. For him to die of a brain tumour, totally devoid of any mental capacity, and drooling and dribbling, to be remembered by his children in a way in which he would not wish to be remembered, was undignified.

But it does not mean that this way of dying, of natural causes in the due course of time, of whatever condition, is undignified for somebody else. It is deeply related, in my view, to our own value systems. There is no one way of dignified dying. If somebody wants active help in dying, where this is related to the whole concept of one's life, that is dignified the provision of it. To die in a different way, which the person himself or herself regards as undignified, is undignified but not for a different kind of person with a different set of beliefs. On the other hand, there are people who want every form of lifesustaining treatment. There was the case in America of my namesake, Helga Wrangly, who wanted life support, everything, even though she was in a consistent vegetative state and was in her 80s. Her relatives said that was what she had always wanted. She had left a living will stating her belief in the absolute sanctity of life and her wish for it to be prolonged by every means, as long as possible. Other people would have thought it undignified to be there comatose, no longer able to communicate, never to be able to again. But from her point of view, I suppose, it was not undignified. So it depends. That is how I use the word. Some people will just say: 'Look, it is not undignified to get a lethal injection'. But what is undignified? You cannot generalise, because it is precisely about values and beliefs which are so deeply connected to who we are and what we are, and how we want to live our lives.

**Mr STIRLING:** It is a bit like the killing and the helping to die. They are throwing the words around with such abandon.

**Dr KUHSE:** Yes. I would use a more neutral expression normally. I am not sure whether I used the term this morning. I would normally call it "respect for" you know.

**Mr STIRLING:** I appreciate that response. It is a commonsense way of viewing it.

**Mr POOLE:** Are you all talked out? All right, I would just like to thank you for spending your time with us. It was very informative, I think. We look forward to receiving your written submission.

---

**Dr KUHSE:** Yes, I shall send you a written submission with some of the key articles that I collected during the last year. I worked in this area in 1987 extensively, to work out the philosophical stuff, and now I just keep up to date. During the last 12 months I have assembled a pile this high. These are just for key arguments.

Maybe I should mention one argument which John Fleming has put and to which I have not responded. This is not [inaudible]. He is putting an argument that voluntary euthanasia infringes the human right to life, which is an internationally accepted covenant. I am not sure whether he presented this argument to you. I want to respond briefly because I think it is one of the worst arguments I have heard in a long while. I am not just saying this because I disagree with John Fleming, but because it is totally turning the notion of a right on its head. The right to life, John Fleming holds, is inalienable. A right can never be inalienable, because if I have the right to something, I can make use of it, or I can decline to make use of it. If I have a right to have a piece of cake, it does not mean that I have to eat it I may if I want to.

A right to life means that nobody must take my life against my will. But it does not mean that I cannot refuse lifesustaining treatment, or indeed request active help in dying. This is turning all traditional, standard notions of a right on their head. A better term would be a duty. That is traditional moral language: a duty. What is internationally accepted is indeed a right to life. Nobody has a right unjustifiably to take anybody else's life. But it does not mean that we must go on living as long as we could. If it meant that, then we could not refuse lifesustaining treatment either. That way we give up our life also. It would mean and this is particularly relevant to John Fleming's own religious background that you could not give up your life for somebody else. In traditional moral theology there have always been martyrs. One person was praised for giving up his life for somebody else, for example, by throwing himself before the lions. Others threw themselves on grenades to save their friends. Those are acts of great courage. But if the right to life means that we could never give it up, all those acts would be ruled out. I think it is a very, very bad argument, and I am surprised actually to have heard it put so often. That is why I am referring to it now.

**Mr POOLE:** All right, we will terminate the meeting at this point. It is 11.32 am.

Thank you once again.

**Dr KUHSE:** You are very welcome.

select COMMITTEE **ON EUTHANASIA**

HEA**RING**

Monday 20 March 1995

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr Jennifer Gray

**Note:** This is an edited transcript.

**Issued: Monday 27 March 1995**

---

**Mr POOLE:** I hereby declare open this meeting of the Select Committee on Euthanasia and welcome Dr Jennifer Gray. Jennifer has asked to appear in front of the committee because she will be unavailable when the committee is taking public submissions later in the month.

Jenny, if you would like to talk to your submission, we have a copy which will be recorded in the minutes at 11.50 am. Then, if need be, we can ask you some questions.

I ask you to state your name and the capacity in which you appear today. You should understand that the transcripts of these meetings will become available to all members of parliament. You will have the opportunity to have a look at your transcript and make any necessary changes if you feel you have been misrepresented in any area, prior to it being sent out to politicians for them to read. It is likely, of course, that the transcripts will be included in the public report, so they will be available to the general public. The transcripts, of course, and whatever you say to the committee are covered by parliamentary privilege, so you cannot be sued, unless you deliberately mislead the committee. While we do not ask you to take an oath, we do ask you to make sure that whatever you say is truthful.

**Dr GRAY:** My name is Jennifer Gray. I am a general practitioner in Alice Springs. I would like to talk both as a general practitioner and as a citizen.

Can I just clear up a couple of things? When you say that whatever is recorded here will be seen by members of parliament, does that mean that if I want to say something to you that I want to keep confidential within the committee ...

**Mr POOLE:** We are happy to take your submission in camera, if you would rather it that way, so that it does not go out it is made available only to members of the committee. It would then still go out to members of parliament, but not as a public document. It would go out as a confidential document.

**Dr GRAY:** So then it would be up to them not to release it any further?

**Mr POOLE:** That is right.

**Dr GRAY:** And their officers?

**Mr POOLE:** Yes, but it is covered by parliamentary privilege. They would be breaking parliamentary privilege by disclosing any of the contents of it. So it is protected.

**Mrs BRAHAM:** Do you want to make it in camera, Jenny?

**Dr GRAY:** Can I decide later?

**Mr POOLE:** Sure, yes.

---

**Dr GRAY:** Because I don't know exactly what I am going to say yet. I think this is a fair summary of what I have been feeling. I have not gone into the detailed provisions of the bill, but I am willing to answer questions if anyone is interested in my opinions on the different clauses.

**Mrs BRAHAM:** You talk about duty of care, Jenny. Duty of care means different things to different doctors but your definition is to provide for their best interests with compassion as far as you can. So you are implying that duty of care also may be in conflict with your duty to ensure their dying is as best you can. Your definition of duty of care is a bit broader, perhaps, than we have been given in the past.

**Dr GRAY:** Okay, I accept that. I agree that my definition of duty of care would involve voluntary euthanasia if that was the absolute best thing for the patient and the family. And if it became obvious to me that that was the situation, then I would regard it as part of my duty as a doctor to assist.

**Mrs BRAHAM:** Some people would say duty of care would be prolonging life as long as they could from a medical point of view. But you are saying duty of care encompasses other aspects as well.

**Dr GRAY:** Absolutely. An extra few days may not be in the patient's best interests, if those few days are completely unbearable. If the patient requests that he or she does not have to live through them, I would certainly take it into consideration.

**Mrs BRAHAM:** The bill says 12 months for the diagnosis of terminally ill. Do you see that as a legitimate length of time?

**Dr GRAY:** The bill says that if it is considered that the person has less than 12 months to live ... I think that is a reasonable length of time, because it is very hard to make a proper prediction. There is a special case of people with HIV, with AIDS, who may have run the gamut of treatment. They can see that their life is limited and suspect that they may become demented, which is common in HIV illness. I would say 12 months would give a chance for these people to be able to make a decision when they know that they can, rather than waiting for a time when they could not make that sort of decision.

**Mr STIRLING:** Jenny, I am interested in your point that for a small number, even stateoftheart palliative care does not work. It simply does not address the pain relief. I guess it is a very difficult thing to quantify, but I am interested in that, and also in how long you would expect them to have to live in that uncontrolled pain situation, even with palliative care. So, the numbers, and how long?

**Dr GRAY:** I cannot really say. Firstly, my experience is not as broad as that of a palliative care physician. Secondly, there is such a variety of diseases, and then also there is such a variety of individuals' responsive clinical courses and response to various treatments, that you cannot say. But in my experience a significant number of people cannot get adequate pain relief. That could mean days or weeks with inadequate pain relief.

---

And it is not just pain relief it is other things such as uncontrolled vomiting, which can make anyone's life complete purgatory.. That is another thing that is not often considered. You have an obstruction in your gastrointestinal tract and you cannot stop vomiting, but the cancer course, for instance, has not reached the stage where you are going to die because of the cancer, but more because of the complications of something else. There are various drugs for vomiting, but sometimes they don't work. Someone keeps throwing up for days and days, as well as being in pain.

**Mr STIRLING:** Could we safely say that we are talking weeks rather than months, if someone is in a situation like that?

**Dr LIM:** I don't think that is right. If on Day 365 a person was diagnosed with terminal cancer, and next day suffered a gut obstruction because the cancer became so big, and could not drink or anything anymore and a naso-gastric tube is inserted to prevent the person from filling up. I suppose surgery can be done to provide a bypass of the obstruction, or a colostomy or ileostomy or whatever to allow passage of the waste products through the body. That might be enough to prevent the vomiting, so that you still have 12 months of a terminal illness except that surgery has intervened to prevent that from happening. So that person's lifestyle is now compromised by having to have a colostomy rather than obstruction. The pain is still another issue, separate from the obstruction.

**Mr POOLE:** So it is difficult to define.

**Dr GRAY:** It is really difficult.

**Dr LIM:** As doctors we all measure other doctors against our own experience and our ability and ethics. Do you see that euthanasia will be practiced by people who are less adequate than we are, who could in fact exploit and abuse the legislation? We think we are reasonably good doctors and people should be like us. But as you know, because of the variability of and the need for medical education, obviously there are doctors in big cities who really are not good doctors. Can we be certain that there are no doctors to exploit this legislation?

**Dr GRAY:** We cannot be certain. I doubt whether there would be doctors who would exploit it for monetary gain because, as you know, looking after someone with a terminal illness is really a moneylosing proposition all over. I could see that there might be someone who is becoming mentally disturbed and might consider that they have a mission to assist the dying, who might push the point a bit, and I see that that could be a problem.

On the other hand, it has been accepted for centuries that doctors have a certain responsibility anyway, in the whole care of patients, and we make decisions all the time that affect people's lives on a daily basis, and society has given us some sort of trust for that. I think the doctor/patient relationship is a sufficiently strong concept, so that most doctors approach that ethically. I think the doctor/patient relationship is something that patients generally understand, without understanding that they understand it. I think they know about it, but would not be able to pin down just quite what it is. The right thing will be done by them, and that is what they expect. I think that is a sufficiently strong concept for 99% of doctors, but I can see that doctors who are mentally disturbed could decide that they have a mission in life. It would be hard to guarantee that no one could abuse it.

---

**Mr POOLE:** Would it not be true to say, though, that there is nothing to stop a doctor with a mission in life from doing that now under the terms of the Natural Death Act? At least in this situation you require the presence of two doctors, and presumably if one doctor was asked to sign a document professing to the competency of the patient, and the patient has indicated a desire to be assisted in their own death, the doctor would take into consideration his or her colleague's point of view. I do not see a doctor just walking in and agreeing to sign without discussion between the two of them.

**Dr GRAY:** I think you are right. I think that is a very strong safeguard. It probably should be kept in. I agree that it would probably pick up most doctors who are not really acting in the best interests of the patients. I think having two would be an appropriate safeguard.

**Mr POOLE:** One of the arguments put to us for the bill is that it simply brings above the table things that are already happening now.

**Dr GRAY:** Exactly. These days it is up to one doctor, because one doctor is not going to tell anybody else. He or she is worried about legal repercussions.

**Mr POOLE:** Yes, and they have the ability to sign the death certificate, if they are the personal physician.

**Dr GRAY:** That is right the death certificate, which is another little crime that is going on. There are several crimes going on at present. There is what you might call murder, if you feel like it, which is euthanasia currently. There is not being honest on a death certificate, which I am sure is a crime. And there is stealing drugs to do the job. It is not just one offence we are talking about.

**Mrs BRAHAM:** People expect that we are going to open floodgates. In your experience, say in Alice Springs, what sort of numbers are we talking about?

**Dr GRAY:** Really very few, because of the people who die, about half die of heart disease, which usually is either very quick or reasonably fast, although there are some who linger on with congestive heart failure, but it usually sorts itself out. One quarter of people die of cancer and 95% of them would die in a way that they probably would regard as satisfactory. They die with adequate pain relief and [inaudible] terminal event. So we are talking about very small numbers. An average GP would be put in the position only once every couple of years, I would imagine. There are really not very many in Alice Springs.

**Mr POOLE:** Marshall Perron has said I do not want to hold him to this, it is just something in the back of my mind that possibly 14 up to a maximum of about 20 people per annum would be affected by the bill in the Northern Territory. Do you think that would be reasonable?

**Dr GRAY:** That sounds a reasonable ballpark figure, yes.

---

**Mr STIRLING:** You might have to be careful how you answer this. I am interested in the practical applications how it would be done by a doctor, [inaudible] what they would give a patient.

**Mr POOLE:** Can I just ask that we do not end up publishing anything that is going to assist people who should not be able to assist themselves? Maybe that particular thing should be asked at the end of the session. You could end up saying: 'You can do it quite easily with suchandsuch', which just happens to be a household detergent or something.

**Mr STIRLING:** In terms of the bill, on the question of competence, I think you said you are happy with that the way it appears in the bill. [Inaudible] 12 months. But that question of competence, if a person was depressed, ought there to be some step in the bill to ensure that they are not clinically depressed at the time of requesting to die? They might otherwise get through that and go on for quite some time.

**Dr GRAY:** This is a good question. Here is how I would see this whole thing working. Usually what happens, if someone is diagnosed with something or other and you go through all the investigations and treatment and that usually happens somewhere else, such as in the hospital in Adelaide then eventually the specialists say they can do nothing, the patient comes back to the GP. Then we might try whatever palliative things have been recommended or have not been tried. This is usually a fairly long, involved relationship. You get to know these people really well, almost like a member of your family, because you go through so much. When people are depressed, that is something that comes up. I would imagine I certainly would do it myself that most doctors would try everything first.

The discussion of dying crops up from time to time. This is something that evolves over a period of time. It is part of the patient coming to terms with the fact of his or her own death. At certain times he or she would like to talk about some things and not about other things. In the course of that relationship, which often becomes very close, any sort of depression is recognised and treated, and all options are tried. It is not something that is a matter of a day or two, or a couple of conversations; it is a long process.

So that is part of the practicalities of it, and I think that is something that a lot of people would hope would happen, and would assume would happen that if they did have a terminal illness, they would have such a relationship with their doctor and would get to a point where they feel that it is quite within their expectations to ask these sorts of things. After a while people's concept of their whole life picture shrinks down to their own life and death and their own family. All the rest out there becomes really quite irrelevant. So people can talk about these sorts of things.

**Mr STIRLING:** You have answered it in terms of that patient/doctor relationship, and I think that is part of your move for the interstate requirement, so that there is the time to develop a relationship and the doctors have knowledge of the patient.

**Dr GRAY:** I actually do not care about that interstate requirement. It does not particularly bother me if there is one or not, the 12month residency. I only put that in because

people have been saying that people will turn up at Kulgera and find the first doctor and ask for an injection, or something like that. And of course the first ones are us down the street, down here.

I still believe that if any doctor is to be asked this, then that person well, I would myself would review the entire case, review what had been done here, what has worked and what has not worked. I would suggest absolutely everything I could possibly think of first, and develop some sort of relationship and develop some sort of understanding of how that person sees his or her life, their general philosophy, and really get to know that person as far as the illness allows, before I am happy to say that is the only option. It is not just an option, it has to be the only option that I can see the absolute last resort. So if someone came to me from interstate and requested it, I would say: 'We have to do this, that and the other. I want to make a decision over a period of time. I am not going to make it straight away'.

**Mr STIRLING:** Your 12month option would rule it out, wouldn't it?

**Dr GRAY:** If it is a 12month option, yes, that would rule it out.

**Mr STIRLING:** People would seek to access this, I assume, only in the last few months of their lives certainly not 12 months in advance.

**Dr GRAY:** Yes, I actually don't agree that it should be put in. I am just saying that it is an option to do it, if you want, if people are sufficiently cowered by the idea of all these terminal people turning up. But that in itself does not bother me at all.

**Mr POOLE:** It could be an academic question anyway, because South Australia, the ACT and Tasmania are all considering it now. If that does happen, I guess it would remove that obstacle.

**Dr GRAY:** That does not bother me as an obstacle.

**Mr POOLE:** With regard to this hypothetical case of people pouring in from interstate saying: 'I'm dying. Please help me relieve my suffering. That is why I have come here', would you not agree that people at that stage probably would not be in a situation to travel anyway?

**Dr GRAY:** No, that is right.

**Mr POOLE:** It is not as though, as I understand the bill, you would be in a situation to book your time 8 months down the track. It is there, solely in the opinion of your doctor, that he or she will assist you on the basis that you are going to have undue pain and suffering. You would really wait until they reached that stage anyway before you made a decision, because otherwise they would not qualify. You could not say: 'You are going to have pain and suffering next January.

**Mr STIRLING:** I think in the case of HIV/AIDS, they probably can. Someone could take a longterm view, particularly in the last 12 months, knowing what they are going to face, and say: 'I want to do it now, while I can, while I am still mobile'.

**Dr GRAY:** Yes, that situation could arise, but I think most doctors would say: 'Let us wait and see how things go. It may not turn out to be quite as bad as you think, and when it gets to a point where it is unbearable, then we will act'.

**Mr POOLE:** Particularly in the case of HIV, you might be in a situation 6 months down the track, because of the tremendous amount of development work being done, of having a drug that controls most of the problems. In the case of cancer, where you know it is throughout the system, there is unlikely to be anything to fix that particular problem in 6 months' time, whereas at least in the case of AIDS, somebody might develop something not necessarily a cure, but a miracle drug that really eases the pain and the suffering, and people die with a lot of the problems and the trauma associated removed. Who knows?

**Mr STIRLING:** These things put up about an interstate problem do not concern me at all. I think they are [inaudible] the opponents, and I do not think it is likely to happen. I think the figures are probably right. I had never heard those figures mentioned before. That in itself concerns me, that we pass legislation that is going to affect so few, but its opponents will say it has the potential to affect the good of so many. Those arguments are another story, I guess. But if it is done now, on the quiet, and no doctor has been charged with killing anyone, how would you see a situation like that occurring? Give me an instance of a doctor being challenged legally.

**Dr GRAY:** It might come from a disgruntled family member.

**Mr POOLE:** Half of these sort of cases come to light basically because the doctor at the end of the day says: 'This is nonsense. Why should I, for doing something that is right for my patient, have to commit a crime?' The fellow in the States, the suicide doctor, is declaring it because he wants to legalise the system which is already in force.

**Dr GRAY:** In England last year there was a doctor who was convicted.

**Dr LIM:** No, they dropped the charges.

**Mrs BRAHAM:** So do you think that legalising it will increase it? We have already heard that one in three doctors practise it. Do you think that this bill will cause an avalanche? One of the arguments that has been put forward is that it will open the floodgates.

**Dr GRAY:** It might mean that people actually ask for it, whereas before they would not have. The conversation could go along the lines of: 'I can't stand this any more. Can you do something for me?', and the other side could say: 'No, it is illegal', and that would be the end of the conversation.

**Mrs BRAHAM:** How widely known is the Natural Death Act in the Territory?

---

**Dr GRAY:** Hardly at all, I think.

**Dr LIM:** Hardly at all by whom? By the patients?

**Dr GRAY:** By patients.

**Dr LIM:** Every doctor working in the Northern Territory was sent a copy of the Natural Death Act, so I assume they would have read it.

**Mrs BRAHAM:** That is the one stating 'no extraordinary measures to prolong life'?

**Dr LIM:** That is right. I think the average joker would not know, because it is not relevant. If you are fit and healthy, what do you want to know about that for? But I think in a hospital situation, when someone is at that stage of life, you actually address that with the patient. That is when the need to know arises.

**Mrs BRAHAM:** The doctor tells the patient?

**Dr LIM:** It is initiated by the doctor, or the nurse. Let me come back to the practicalities of this bill. One of the clauses says that the patient requires two doctors' signatures to go through this process. If you read it through closely, in fact it is Dr A, who intends to assist the patient, who needs to go through the full process. Dr B actually has only to agree that the person is competent, and has a disease that will kill within 12 months. It does not say that Dr B has to agree that euthanasia is appropriate for the person. I can see a situation where Dr A agrees to assist, and goes to Dr B and says: 'Please see this patient, tell me that he is competent, tell me that he is going to die in 12 months. And Dr B says: 'I don't agree with euthanasia. But on those two terms, I can't say no, because it is right'. So Dr B now has to sign that form, saying that person is competent and will die in 12 months. So the conflict now arises ...

**Mr POOLE:** Why, though, does Dr B have to sign the form?

**Dr LIM:** He does not have to sign the form. But he may be coerced in a situation where there are only two doctors in a town. Dr B does not have to worry about the euthanasia bit. All that Dr B has to concentrate on is whether the person is competent at the time of making the decision that he or she wants to die by active means, and that the person is going to die within 12 months from the disease. Two doctors in the town, and there is nowhere else to go because they are so far away. Do you see the practical problems with that, where Dr B is signing the form, at the same time not agreeing with euthanasia, but signing the form within the confines of the bill?

**Dr GRAY:** I think that is okay. I do not believe that anyone would sign a form if they felt they were being coerced into it. I also think it is unnecessary to have the second one state that euthanasia is the only option, because, as I said before, that is a decision that is made over time in the context of a long relationship. It may be that by the time the second one is called in, the person no longer wants to talk to anyone. He does not want to have to go through the whole process all over again, describing why he or she wants this. I myself think that is enough, that the second one just has to attest to those two requirements.

---

**Mr POOLE:** One would think that you would end up in a situation whereby some doctors who, for ethical or moral reasons, do not support euthanasia would just say: 'Look, I'm sorry, I'm not going to do it'.

**Dr LIM:** But suppose you have two doctors, really a long, long way away. You cannot send a patient away to see another doctor. That happens. What do you do? Do you bring another doctor in?

**Dr GRAY:** Maybe you do. You have to handle it somehow.

**Mr POOLE:** The chances are you would not have two doctors in Yuendumu [inaudible].

**Mrs BRAHAM:** There is also the question of whether a doctor in the same practice should be the second doctor.

**Mr POOLE:** Does it not say, 'not in the same practice'?

**Members:** No.

**Dr GRAY:** I do not think that is necessary, either. I suppose the implication is that there is some sort of game being played, some conspiracy. But there is a reasonable chance that a doctor in the same practice would know the patient anyway. It would make it that much easier to organise.

**Mr STIRLING:** Would you change the bill in any way? Are you happy with it as it is? Do you see weaknesses, deficiencies, things that should be in there but are not?

**Dr GRAY:** I would probably have to go right through and read it. I am not qualified to talk on the legal aspects. I think that needs to be looked at. I would just make the comment that some people have talked about getting a lawyer involved in it, or a coroner or a coroner's constable or something. I do not think that is a good idea. I think they probably should be kept out of it. I think that the bill should be tight enough so that it is a legal thing, that it would be upheld to be legal if challenged.

**Dr LIM:** At the forum they had upstairs, one of the matters raised was Dr A and Dr B signing the form, with the patient, and then at a later stage one of the doctors wants to withdraw. The bill at present does not allow that. Dr A is happy to do that for the patient. Dr B signs the form. Six months, 11 months, down the track something happens and Dr B says: 'Hang on, I want to withdraw that', and Dr A says: 'Sorry, I have the form'. What happens then?

**Dr GRAY:** I think you should have the right to withdraw your signature.

**Mr POOLE:** Do you really see that people are going to be signing a consent for somebody to utilise this act in 12 months' time?

---

**Dr GRAY:** No, I think the timeframe could be a lot tighter. Something could happen in that intervening time that could lead you to change your mind.

**Mr POOLE:** To me it is a grey area of the bill. While we say things like 'expected not to live beyond 12 months' etc., my understanding was never that you could make a decision 12 months in advance to utilise this bill and, say, be assisted next Christmas. That is not the idea of the bill.

**Dr LIM:** I do not know, because the bill does not say when you have to implement the decision. It just says that a patient who has 12 months of life left can decide any time to exercise the privilege of the bill. It does not say within 7 days, within a month, within 12 months. I would have to assume that you can make a decision at any time, and you can then decide on a particular day that you want to do it now. The form is already signed and everything is in process. It is no good my saying: 'I am living in the Northern Territory and I will wait until I am ready'. By the time that I am ready, I may not be competent to make the decision because of brain tumours as a result of secondaries, whatever.

**Mr POOLE:** I do not think the intention of the bill is that you can sign the form when you are competent and wait till you are incompetent for it to be carried out. The idea of the bill is that you sign when you competent and it is carried out when you are competent.

**Dr LIM:** Yes, I agree. But your competency does not deteriorate in that 12 months. Dr B can, for some reason or other, whether [inaudible] not going to do that, and then withdraws his signature, what happens to that process?

**Mr POOLE:** Yes, maybe there is a case for putting on the consent form that it is only applicable for 30 days or something. And if the patient does not hold up the hand and say: 'Right, let's do it', you would have to redo the process to get it.

**Dr LIM:** Every 30 days, yes. Of course, the patient has the right to rescind at any time, but neither medical practitioner ...

**Mr POOLE:** The patient doesn't have to rescind, because the patient, at the end of the day, still has to say: 'Let's do it'. It does not matter what is written on the form or who signs it, it cannot be done without the patient's consent.

**Dr LIM:** Dr A is not going to come along with a piece of paper and say: You signed this 12 months ago I'm going to do it today'. I understand that. But what happens if Dr B changes his mind? I think we might need to put something in there to safeguard that, because if the doctor changes his or her mind ...

**Mrs BRAHAM:** For good reasons, though.

**Dr LIM:** For whatever reason. What is a good reason? That is subjective.

**Mrs BRAHAM:** He signed it in the first place. Should he be able to withdraw without seeing it through?

---

**Dr GRAY:** The situation could have arisen where Dr B thought the person was mentally competent, and then a week later decided that person had a treatable depression.

**Dr LIM:** I assume Dr A would have picked that up anyway. I think something needs to be done to protect Dr B, so that at least the doctors have the right to rescind. Another scenario discussed at the forum upstairs was Dr A and Dr B both consenting, then for some reason Dr A changing his or her mind. Suddenly the patient is left without an agent, at a time when the person is no longer competent to make the decision. Suppose an HIV patient comes along and says: 'I know my dying process includes dementia. There will come a time when I can no longer make a competent decision. Therefore I need to sign this form in time. Then he develops dementia. This bill, if you have a 30day clause or whatever, will exclude them, because you do not know when they are going to become incompetent.

**Mr POOLE:** Then they are covered by the provisions of the Natural Death Act, if they are incompetent.

**Dr LIM:** But the Natural Death Act is not giving euthanasia. It just says you do not get treated. The issue, then, is that a patient with HIV/AIDS says: 'I had better sign this form today. Make sure that it is applicable for 30 days, 6 months or 12 months, whatever, and just make sure it is locked in now. And when I come to the stage of losing my mental capacity, do something put me down'. Later Dr A is no longer prepared to do it. Suddenly that patient is disenfranchised. He or she is no longer competent to negotiate with anybody else.

**Mr POOLE:** I understand what you are saying. I do not think, though, that we can pick up that, because then you are changing the bill in effect from voluntary euthanasia to involuntary euthanasia.

**Dr GRAY:** Yes, I agree.

**Mr POOLE:** Marshall Perron has specifically said that the key to this is that it is a bill for people who hold up their hand. If they do not have the ability to hold up their hand and prove that they are mentally competent, then the bill is not for them.

**Mr STIRLING:** Jenny, would you accept that, compared with 20 or 30 years ago, doctors are much more honest with their patients today about death and dying, and that generally husbands and wives face the situation much more honestly than perhaps 20 years ago, when a doctor might tell a wife that her husband was dying, but did not tell the husband himself?

**Dr GRAY:** I think that used to happen, but not very often, and I think it happens even less often now.

**Mr STIRLING:** But are there still cases where a doctor would not tell? There must certainly be cases where spouses, while they know one has cancer and they know it is terminal, they still do not confront the question of dying and death between them.

---

**Dr GRAY:** I am sure a lot of people find it difficult to talk about those things, constitutionally and ...

**Mr POOLE:** You must have the situation where the husband has cancer or whatever, and he says: 'I don't want you to say anything to my wife. I'll tell her in my own time'.

**Dr GRAY:** I think that happens, but after a while it is very hard to keep those sorts of things secret. But what is the implication of your question?

**Mr STIRLING:** It is an observation. Obviously, there has to be upfront honesty between everyone certainly the patient and the doctor. It was from my own experience, that was all. My father died of leukemia in 1963. The doctor always told my mother not to tell him, though of course he must have known, because he was receiving frequent blood transfusions and [inaudible].

**Dr GRAY:** I think that is probably rare to the point of nonexistence today.

**Mr STIRLING:** I just wondered, because I was thinking in the context of one of the submissions that I want the committee to get around to discussing. It is one thing to know that you are dying, but it does not mean that it is discussed upfront between the couple.

**Dr LIM:** Doctors tended to be very paternalistic in the old days, in the 50s and 60s. I think in the 70s there was a huge change in doctor-patient relationship. There is now a lot of discussion and negotiation with the patient and allowing the patient to be in control of their medical care. It has changed quite a lot.

**Mrs BRAHAM:** Patients probably question doctors a lot more these days. They want to know a lot more.

**Dr GRAY:** We are assuming the patients we are talking about have enough selfconfidence and trust in themselves and their families to be able to talk about these sorts of things. Of course there are always people who cannot. The bill is not for them, either.

**Dr LIM:** Do you think doctors should broach this subject with patients anyway?

**Dr GRAY:** While it is illegal, no. If it were to be legalised, I think in certain situations, depending on the context of the relationship, you could say something like, 'You realise that there is legal euthanasia in the Northern Territory?', and just leave it at that. That might even be the extent of the discussion.

**Mr POOLE:** I guess it would be more likely that a doctor would say that a lot of pain and suffering could be expected, and when it came to that stage the options available would be discussed.

**Dr GRAY:** It would be just great to be able to say that for everyone concerned.

---

**Mr STIRLING:** You do not think there would be a danger that the person may take that to mean that they are in some way a burden to the system? Just by virtue of the fact that it has been mentioned by the profession?

**Dr GRAY:** I suppose it is possible, but I think it highly unlikely. Usually a relationship is built up over a long time, involving lots of things, and presumably the doctor would be showing on a daily basis his or her care for the person. Ideally, patients would see it in that context, as a continuation of caring, rather than a doctor's ultimate problemsolving.

I know that opponents have said that people would feel obliged to ask for it, to relieve other people of bother. Firstly, I think this would be really rare and unlikely. Secondly, a blind man on a galloping horse could pick it up not just doctors. It would usually be obvious if this were going on.

**Dr LIM:** There is a glib saying, 'Please put Mum out of my misery'. It is not Mum who is suffering the pain. The person is really saying: 'I'm helpless. Do something. Put her down, so that I no longer feel helpless'. Do you think that is a fair comment, or do you have any comment on it?

**Dr GRAY:** I can see how some people would say that, but I think it would not happen very often. Such a request would be given very short shrift, because the duty of care is to the patient.

**Dr LIM:** I am not saying that a person would actually say those words. A lot of people say they support euthanasia because they do not want to see their loved ones suffer. But is the suffering the patient's, or the observer's?

**Dr GRAY:** It might be a little bit of both. It is your philosophy on human nature. I would like to believe that most people would support it on the basis that it would be a relative suffering who would be relieved, rather than themselves.

**Mrs BRAHAM:** You are saying practically it would be correct that a doctor should have a longterm relationship with the patient. Do you think that should be one of the safeguards in the bill?

**Dr GRAY:** That you have to have been involved with a person for a period of time?

**Mrs BRAHAM:** Then all your decisions are based on a longterm understanding, mentally and emotionally, assessment of a situation.

**Mr POOLE:** What happens [inaudible] if that is the situation [inaudible] ethical question and a moral dilemma, who just says 'I don't support euthanasia'. If you did not know that, and he says: 'Because of my moral and ethical dilemma, I'm not prepared to go to another doctor and say I think ...'

**Dr GRAY:** That is an interesting question. You could ask someone to take over and make a very rapid assessment of what is going on. Then you might decide within a week or so that it is a reasonable thing.

**Mrs BRAHAM:** However, in that situation myself I would probably establish fairly early on that I had a doctor there who would establish a long, close, trusting relationship, with a view to knowing what I may want.

**Dr LIM:** If the legislation is available, I think most patients would do that. A lot of Jehovah's Witnesses now would ask: 'Are you a doctor who believes in transfusion of blood in all circumstances?', and they actually establish that in the first week of seeing you, so that they know exactly where you stand.

**Mrs BRAHAM:** If the bill is passed, you would want to see it go down a track where doctors actually are reasonably well identified as being people who will at the end of the line be prepared to say they would cooperate.

**Dr GRAY:** Word gets around, I suppose.

**Mr STIRLING:** The AMA remains, from what we are led to believe, implacably opposed. What reasons have they put up just the dangers of it?

**Dr GRAY:** I really do not know. They say it is because doctors should prolong life rather than end it. Brendan Nelson is being quite hypocritical about this. He has stated this, but said: 'However, I have done it, and it is good that you can do it in certain situations if the need really arises but in general, no'. I think that is fairly hypocritical.

**Mr STIRLING:** Saying it is sort of all right, but we do not need a law.

**Dr LIM:** He is going to front up [inaudible] to talk to us. It will be interesting to hear what he will say.

**Dr GRAY:** The viewpoint that it goes on now, it works all right, let us leave sleeping dogs lie is, I think, immoral and hypocritical. You still have sleepless nights thinking: 'Who is going to find out about this? Who can I tell? Who can't I tell?' Visions of winding up in the Alice Springs watchhouse, ringing people up to get you out.

**Mrs BRAHAM:** I suppose at the moment doctors are wearing it, basically carrying guilt.

**Dr GRAY:** It is not guilt. You would not do anything deliberately that you know you are going to feel guilty about. It is the worry about being found out. This is another point, that it is not good to have situations where certain things are illegal if the law is not going to be upheld. It only encourages community disrespect for the law. If people decide to obey one part of the law but not another, because it goes against their conscience, it is not a good situation.

**Mr POOLE:** All right, stop the tape.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 9.15 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative: Australian Federation of Right to Life Associations

Mr Greg Smith, Barrister and also President,Right to Life Association

(NSW) Inc.

Mr Thomas Kiely, Secretary, Northern Territory Right to Life Association

**Note:** This is an edited transcript.

**Issued: Wednesday 5 April 1995**

---

**Mr POOLE:** I declare open this hearing of the Select Committee on Euthanasia on Wednesday 29 March 1995, and welcome the following witnesses on behalf of the Australian Federation of Right to Life Associations: Mr Greg Smith, barrister, and president of the New South Wales association, and Mr Thomas Kiely, secretary of the Northern Territory association, who are appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before the committee are not required to take an oath or make an affirmation. However I remind you that the information you give to this committee must be truthful. I also advise that the committee has authorised, for the purposes of this inquiry, that the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply.

Witnesses do have the right to request that their evidence be taken in camera or remain confidential. Would you please advise us now if that is the case.

**Mr SMITH:** Not as I anticipate it.

**Mr POOLE:** For the Hansard record, please state your full name and the capacity in which you appear today.

**Mr SMITH:** My name is Gregory Eugene Smith. I am a barrister and Crown Prosecutor in the State of New South Wales. I am appearing on behalf of the Australian Federation of Right to Life Associations. I am the president of the NSW Right to Life Association, which is the largest body in that group.

**Mr POOLE:** Thank you, Mr Smith. Now, we have normally adopted the format in these meetings where we give witnesses the opportunity to make a submission to the committee, and then go into a general questionandanswer session if committee members want that to proceed. Are you happy with that format?

**Mr SMITH:** Yes. I propose initially to highlight the matters contained in our written submissions. I have personally made a submission as well, as an annexure to the Right to Life submission, which specifically addresses clauses of the bill with which I see problems. But I propose to go firstly through the Federation of Right to Life Associations submission. Do you all have a copy?

Page 1 is an introduction. Page 2 commences an examination of the common law tradition, putting preservation of life as a very high priority in our legal tradition. I remind the committee that the Northern Territory, although it has a criminal code, has basically picked up the traditions of the common law that have come down through the centuries and have been turned into statutes previously. The provisions of the code, particularly in part 6, that deal with offences against the person specifically the homicidetype provisions pick up largely the common law tradition and practice.

---

The first aspect that I take is the legal position at common law so far as homicide is concerned in treatment of patients. I set out extracts from the Tony Bland case, which you are probably all aware of probably sick of hearing about. Nevertheless it is a very important case that is persuasive in courts throughout Australia, although perhaps not binding fully, the High Court having sometimes gone a different way. Although it is not looking at a case of euthanasia, it is looking at a case of someone suffering from a persistent vegetative state. They do examine the whole question of sanctity of life and the importance of the position of the medical profession visavis their patients.

At page 5 I look specifically at this concept of the sanctity of life, which some people might think is a religious issue. It is not. It is a concept developed by the common law courts over centuries. Admittedly it probably had its genesis in the JudaeoChristian ethic, which inspires much of our common law still. In that analysis I look at more extracts from the Tony Bland case, a decision of Justice Thomas in the Auckland Health Board v. the AttorneyGeneral of New Zealand case, where a person with not a terminal condition but a seemingly incurable condition was also allowed to be ... They stopped feeding and they took him off a ventilator. Again the emphasis in that case was the importance of life and the sanctity of life.

Next, I go to McKay v. Essex Health Authority. That looks at the commencement of life whether a child who is born extremely handicapped should have been killed before birth, that the doctors should have identified a handicapped position. The policy of that decision, by the English Court of Appeal in a case that has been followed in Australia, is that the courts do not recognise that someone should never have been allowed to be born. Admittedly that is at the other end, but it is still looking at this question of the sanctity of life.

I then go to cases dealing with the courts' abhorrence of assisting suicide. I do this because what you are looking at here is a piece of legislation which, if enacted, would be unique in British Commonwealth countries and in the western world apart from Oregon, that law being under a challenge which is likely to go to the Supreme Court of the United States on constitutional grounds remembering that the Dutch law still prohibits euthanasia, although it is honoured more in the breach because of medical guidelines that have been brought in. Nevertheless, this would be the first piece of legislation in the western world made by a parliament, whereas the Oregon law was passed by a very narrow referendum, 51% to 49%.

I take you to a short review of the Peter Schneidas case. A prisoner who was trying to starve himself to death in protest sought the court's assistance to stop the Corrective Services doctors from treating him and feeding him. Justice Lee of the NSW Supreme Court there said the court will never assist someone to kill themselves, that it is abhorrent to the notion of the rule of law in our courts. That was in 1983. In 1992, Justice Powell in the same court ruled on a case in which a number of Asian refugees in an internment camp went on a hunger strike in protest of conditions. He set out similar principles, followed Schneidas. In our submission we have annexed the judgment so if you want to have a closer look, you can.

---

In the Victorian Supreme Court in 1988, Justice Fullager ruled on the case of Kinney, a man who had attempted to commit suicide by overdose, having been charged with murdering his motherinlaw. His wife sought to stop the doctors from performing emergency surgery to allow blood transfusions to be more easily performed. The court again refused to interfere with what the doctors were doing on the basis that that would have, as it were, assisted in the suicide.

In Nancy Crusen's case, an American Supreme Court decision, the court would not allow feeding and ventilation to be stopped. It held that the law of the State I have forgotten which state was valid. The court, particularly Justice Scalea in the majority, went into great detail as to how the American tradition and the common law, which they have picked up as we have from England, emphasised for instance that other citizens could lawfully stop a suicide. That exists in your law and exists in every

State and Territory law, as far as I am aware, in Australia. That really puts the lie to the suggestion that you have the right to choose suicide, when somebody else can come and stop you and use force if necessary knock you out, put you in a straitjacket, give you some drug to knock you out, or anything to stop you committing suicide. It usually does not get to that stage, but Scalea goes into great detail.

A case that is not that well known, but perhaps the most important examination of all these issues, is that of Nancy Rodriguez. It was the subject of a television program recently. She was a leading voluntary euthanasia supporter in Canada. The Supreme Court of Canada in 1993 reviewed the constitutional validity of the criminal code provision that made assisted suicide a crime whether it was inconsistent with the charter of rights and freedoms and by majority the court held that that law was a valid law. Justice Sopinka gave the leading judgment. I set out in detail extracts from his judgment. He examines right across the western world the various committees, the various courts, the various human rights commission examinations of euthanasia, and examinations of recommendations for changing the law, and comes down very strongly on the side of preserving these offences and not allowing exceptions. He points out that perhaps the hardest cases are the cases we are talking about, where someone is in the dying stages of life, but comes down very strongly in finding that to make an exception there cannot be controlled and would lead to abuse. The same law that applies to you and me should apply to everybody. Once you start making exceptions to the homicide laws, you leave yourself open to chaos.

I then move, in page 24, to Australian laws permitting the use of force to prevent suicide. It is just a brief one; I have already mentioned that.

Then I examine the defence of necessity, and its unavailability in murder charges. This has considerable significance, because the Dutch decisions which allowed the guidelines to be developed, in the mid-1980s particularly by the Supreme Court but earlier in the 70s by the lower courts, were supposedly based on the defence of necessity. The defence of necessity is supposed to say that a person can justify his crime of necessity if he faces imminent and urgent peril and there is no other way out that is basically it and his act is not out of proportion.

---

Unfortunately the only area where the defence of necessity has been allowed consistently in this country is that of abortion. I know this is not an abortion discussion, but 80 000 Medicare abortions a year, compared with perhaps 240 000 live births, indicates that necessity is not being strictly enforced by abortionists and doctors who are performing abortion. You will always find somebody who will say: 'I think there is a serious danger'. Then you are saying: 'It is necessary', as a common thing. And so you virtually have carte blanche.

That is what has happened in Holland. By the Dutch courts saying that necessity should allow euthanasia when doctors perform it, they have basically opened up the floodgates to euthanasia. Reputable academics and others have analysed the Dutch reports to show that now more than 50% of euthanasia cases are nonvoluntary. The abuses in Holland are rife.

What is being suggested here is, we would say, an even weaker and looser law that would mean that there would be more abuses in the Northern Territory, because of the possible effect on other states, and certainly the fact that other people can come to the Northern Territory to die. It can be compared with the practice of abortion in Australia. Places like Tweed Heads have become havens for people from Queensland who want abortions thousands of women. Irish women go over to England. If you cannot get it in one place, you go where it is available. Once euthanasia is available in Darwin and the Northern Territory generally, other people I am not saying it will be a real lot, but it will grow as time goes on will come seeking it. And you will have your ordinary frail citizens fearing more and more that every time they go into hospital, they might get the needle.

I then apply the questions raised in 1884 by Lord Coleridge in the Dudley .v. Stephens case. That is the one that held that necessity is not available as a defence to murder. After a shipwreck healthy, strong men killed their cabin boy and ate him. They were rescued 3 days later. It was a horrible case. Nevertheless the court said fear of starvation was not justification. The strong will always kill the weak, and the law cannot sanction that. To some extent that is what is going to happen here. The weak not only physically weak but mentally weak people who are depressed, people who are uncertain, and people to some extent who are pressured by thinking, 'I am just a bother, an inconvenience. I am causing trouble. It would be better if I was out of the way', those sort of people who normally would not consider euthanasia may well be pressured into it if this law is enacted.

I refer at page 28 to the NSW government's response to this question, treatment of the terminally ill. A discussion paper was circulated after a large number of submissions were received. A forum was held, jointly sponsored by the Health Department and the AMA. The views of the audience, which largely represented the people who made the submissions, indicated there was strong resistance among people who treat the terminally ill, religious people, the prolife people and philosophers, as well as medical insurers and lawenforcement groups, against legalising euthanasia, even against any legislation. They decided the common law was sufficient, but decided to bring in guidelines. We are not totally happy with the guidelines I suppose nobody ever would be but they certainly are against euthanasia.

That is the largest State in the country; in many ways it influences other States. We have outspoken supporters of euthanasia there such as Dr Andrew Refshauge, who may become the deputy premier within the next week or so. But in letters to me recently he has indicated that his party has no intention of introducing euthanasia legislation. That is also the policy of the outgoing Liberal/National government. Dr Refshauge has indicated that he is not interested in bringing in private member's bills, either. He does not believe that NSW needs that or wants it.

Then I go to the House of Lords select committee on medical ethics and examine its findings on this question. An influential member of it was Dame Mary Warnock, who is not in any way seen as a prolifer. She supports causes opposed to the prolife movement. Yet that committee unanimously came down against euthanasia. Without any disrespect to this committee, they spent many months. They went to Holland and examined the Dutch practice comprehensively. They had cases which prompted the inquiry something that has not happened here cases which really tested the law: the Bland case, the prosecution of Dr Nigel Cox, who was convicted of attempted murder after killing a patient at her request. They still came down against it, on the basis that although there are some very sad cases there, they are in the minority, and really the common interest of the community requires that the laws against homicide remain the same, because they are really the foundation of the whole criminal law system in our modern society. It is an offence to kill someone else, even if they want it, and that has always been the tradition of the law, at least for many hundreds of years.

Bearing in mind the availability in England of very good palliative care services England has led the way they urged that they be improved. That is what we should do here. You do not have much in the way of palliative care. There are some very dedicated people doing it, but there is no hospice. There is not really a big commitment by this Territory to palliative care. Taking the Dutch experience, you are unlikely to go that way if you are going for euthanasia. Holland has virtually no palliative care services. That is a real problem which has to some extent been aggravated by the continuance of the euthanasia practice.

I refer at page 30 to a paper that I have attached dealing with suicide among Australian youth. There was recently a national conference in Sydney on this problem. All sorts of solutions were suggested, including some by Dr Carmen Lawrence, who I note came out in support of this legislation without even seeing it, and encouraged other states to do the same. She would surely be speaking from the point of view of balancing the health budget. I say that tongueincheek, but that seems to be the main interest of the Commonwealth so far as health services are concerned these days cutting the cost. That just makes older people feel more vulnerable, makes them feel more guilty, when they have to go into a hospital. I have a relative who is terminally ill, and he is not feeling very happy about all this discussion, I can assure you. It just makes them feel less secure, although I am sure that he is safe.

At pages 30 to 31, we refer to the Victorian Voluntary Euthanasia Society's draft bill. That is Marshall Perron's model, I have no doubt. The provisions of clause 6 are almost identical, or were in the original draft. Many of the other provisions are similar, although that Victorian draft bill did provide that the method of euthanasia be by drug. This bill does not not that I support any bill, but that would be a weakness about this bill. You could go and throw

someone over a cliff, and if you were a doctor or the doctor was there, arguably that would be justified under this legislation. I suggest that would make a mockery of this law. My being able to say that shows that there is a problem already with this draft bill.

The Victorian bill, which was drafted as I understand it by Prof. David Kelly, who is an active member of that euthanasia society, was described by Dr Brendan Nelson at the AMA forum on death and dying last July in Canberra as something that you could drive a truck through. I sought to cross-examine Dr Kelly on the bill at that forum, and was threatened with a defamation action. Nevertheless, I suggest that that bill has been drafted by people who are fanatically supportive of euthanasia. While some would say that we are fanatics, I suggest we are not. What we are doing is basically seeking to preserve the law as it is, so we are not taking an extreme point of view at all. We do not want to ventilate corpses. We do not want to treat people like Lazarus and bring them back to life if they are dead. We are not extremists at all. We are prolife, and we are strengthened by the fact that our view is the same as the view of the law and medical ethics. So we speak from a strong position. Those who wish to change that position should not just be attacking the prolife movement, because they are attacking the status quo. To change that fundamental homicide law, one would need to have very tight, carefully drafted provisions that no reasonable commentators could find fault with. And yet this bill contains many holes.

If you have time and I know you probably have millions of pages to read there are some attachments there. There is a very good submission by the British Society for the Protection of Unborn Children. As I understand it, that was drafted by Dr Anthony Fisher, who is a Dominican priest. He has written extensively on IVF, abortion and euthanasia. He has a brilliant mind, and a reasonable mind too. That submission sets out the legal, ethical and moral position.. Just because we are making laws, that does not mean we should not take into account morality. We all have to obey morality to some extent, even though some of our views might be different. There are common grounds in morality, and that is one of the bases for keeping the homicide laws intact.

On the Dutch approach, I suggest that you read what Justice Sopinka said. I say that the Dutch approach is full of holes, and that this bill is largely based on the Dutch approach. The Dutch guidelines are very similar to clause 6 of this bill the conditions that have to be satisfied except in some ways they are tighter, because in the Dutch situation you have to have exhausted all other ways of providing relief. In this bill, that is not required. A patient with a kidney condition, for example, could say to himself or herself: 'I do not accept that I should stay on dialysis. I want to kill myself', or: 'I do not want to stay on dialysis. I do not like it it is inconvenient'. That will render that person dead within a reasonably short period of time if he or she has a bad condition. That person's choice is paramount in this legislation. It is not so in Holland, not under the guidelines. I am not saying they are followed, but you must look at something. The guidelines say it has to be the last resort. Here it does not say that, in clause 6.

The idea of having a second doctor, we submit, is no real protection. Where doctors decide to run a euthanasia practice, they could keep the patient within that practice and just 7

---

agree with each other. In Holland it is supposed to be an independent physician. I do not know whether that works really well, but at least they do put forward the concept of independence. This legislation does not. The agreement of just any other doctor it could be the husband or wife of the doctor gives them immunity from any prosecution, any disciplinary action, any civil suit.

An important observation by Justice Sopinka in the Rodriguez case was this: 'The critics of the Dutch approach point to evidence suggesting that involuntary active euthanasia, which is not permitted by the guidelines, is being practised to an increasing degree. This worrisome trend supports the view that relaxation of the absolute prohibition takes us down a slippery slope'.

At pages 19 and 20 of my submission, I refer to what Justice Sopinka said about the rejection by the same vote, 54% to 46%, of referenda for assisted suicide in Washington state in 1991 and California in 1992. He said: 'In both states the defeat of the proposed legislation seems to have been due primarily to concerns as to whether the legislation incorporated adequate safeguards against abuse'. He went on to say, as I read him, that there are just no safeguards that can stop abuse. We suggest that the Perron bill does not stop abuse as currently worded, and that no bill on this subject can stop abuse.

There is no provision in this bill for independent scrutiny by the coroner or a body such as the Guardianship Board or the Commissioner of Police or the AttorneyGeneral or the Health Department, or anyone. A patient's signature could be forged. If you had two doctors practising in partnership, that could easily be done. This would make the procedure illegal, but apart from the twodoctor requirement, who is going to scrutinise it unless somebody else knows about it and blows the whistle? If people were going to do that, they would do it secretly.

In the John Smith case, he and another doctor forged a certificate under the English Abortion Act. Doctors are not immune from breaking the law. Just as in every other profession, including my own, there are crooks. There are sharp practices, there are profiteers. Euthanasia may well become a way to make a nice earn. It sounds terrible, but abortion has. Why should euthanasia be any different?

The medical profession here, and the nursing profession, tend to have a culture of not dobbing one another in. There are obviously abuses occurring at the moment throughout Australia in the area of euthanasia. People are being killed at their request and the doctors are not being prosecuted. The Victorian example again, Victoria trying to pressure the Northern Territory and the rest of Australia, Victorian voluntary euthanasia people Dr Rodney Syme, a very active member, a supporter of the bill here, at the time you are about to start your public sittings, comes up with what has been described by Dr Brendan Nelson as a stunt to invite prosecution of himself and a number of other doctors for cases of assisted suicide and murder.

---

Mr Kennett, I think correctly, has rejected that. Why should a prospective accused call the shots as to what case he is going to be prosecuted for? He could pick the hardest of cases. He has admitted that he has fabricated evidence in the past and lied to police. Could you say he is a man of good character when he comes forward after admitting those things, that his credit is the credit of an honest man, when he has admitted all that? He is willing to be tried, but he said on television the other morning, on the Today Show, that he wants the jury to decide what is the correct law on euthanasia. That would be an absolute usurpation of a jury function.

I prosecuted a rape trial last week. I thought the man was guilty. The jury acquitted, and the jury were instructed by the judge and addressed by counsel. They were advised to put emotion out of their mind, to forget about whether they thought this poor 15yearold girl had been hard done by, whether her de facto stepfather had been molesting her for years, and to put aside any sympathy for the family because the girl had split it. Juries are told to put such things out of their mind, and they regularly do.

But in a euthanasia trial, which would be very rare in this country, with all the attendant publicity and fuss and people outside the courts with banners and all that, what chance is there of a proper jury verdict? And if the jury did acquit, as they sometimes do on these charges, because sympathy does still creep in, that would not change the law. What he wants to do is use that in a domino effect to try and knock over the laws through public pressure, just as Exit in England used the Nigel Cox case and the House of Lords case, but failed. That is what they are trying to do down there, and they are trying to influence you, this committee, among other things. I suggest that you reject that aspect and look at the hard, cold law and the principles that the law has entrenched as fundamental.

Turning briefly to my submission on the legal aspects, I set out in detail the various provisions of part 6 of your criminal code that deal with homicide, suicide, manslaughter and associated offences. They apply to everyone in this Territory. Why should an exception now be made for one small group of people which may undermine the protection that those provisions give to the vast majority of citizens? Once you start making exceptions to those rules, how can you honestly forbid other actions for instance where a husband wants to kill his wife and the wife wants to die, but does not want a doctor involved? Or where they give birth to a severely handicapped child again, the pressure will be on to let that baby die, or even kill it. As time goes on, as in Holland, the law may not be practised any more. Once you have a law that validates some of that behaviour, how can you really withstand the pressure to allow the rest of that behaviour? Then everybody feels threatened.

I think it is in Norway now that once you reach 70, you cannot go into a public hospital. They say: 'You are just useless to society you have to pay your own way'. That is a practice that is occurring here to some extent. People are questioning how much it costs to keep people alive, and when you have legislation like this, it gets worse.

---

You have provisions, apart from part 6, dealing with preventing crime by necessary force. Under section 26(3), a fundamental provision in your criminal code, a person cannot authorise their own killing or authorise grievous harm to themselves, except where it is medical treatment. In my submission, in no way could you call killing someone medical treatment. It is an abuse of the word.

I point out in my submission, which is part of the federation's submission, the fact that there is no definition of terminal illness, which really leaves it up to the individual doctor to decide who is terminally ill. We get people like Doctor Hunt in South Australia, who runs a hospice. He supports so I interpret what he says killing people who are depressed, who are not terminally ill. They have a condition which will ultimately kill them, but would not satisfy the 12month provision. Because they are depressed, you put them out of their misery. You would have pressure, and there would undoubtedly be cases where doctors would be persuaded to do that, particularly if you do not have a definition. It would be much easier for them to say: 'I acted according to the Act'. And who is going to look at it? The coroner does not. All the coroner does is act as a post office.

Extraordinary measures are not defined. They need to be. What happens if somebody changes their mind halfway through the euthanasia process? That has happened in Holland. If someone changes his mind, the doctor would be safer to rely on the certificate, because if that person is then saved but is braindamaged or something like that, the relatives may sue for negligence. Does the certificate or the direction act as a protection where the direction is revoked? That has not been addressed in the bill. Would it cause a split among medical staff at a hospital? There is no guidance from the bill on what to do in those cases nothing.

There is no independent observer required. If you are going to be hanged, or executed in the electric chair, there have to be independent observers to make sure everything is done regularly. I am not knocking doctors, Dr Lim, but they are just like anybody else and they have human failings. I know that most of them are very ethical, but there is noone watching what they are doing. They are the ones who are party to this. They would be very emotionally involved in it. I apply the same principle that applies to lawyers: he who acts for himself has a fool for a client. There needs to be other scrutiny. The coroner would be someone who might be appropriate, to review each case.

The House of Lords has said and Australian courts have said, in relation to sterilisation cases, that you should go to a court before you sterilise a minor or a handicapped person. The House of Lords has said that before you turn off the food for a PVS patient, you should go to a court. There is none of that here, and yet those decisions are made because there are crucial things happening to people. Either they are dying or their fertility is going to be stopped. The courts think that is serious enough to have independent scrutiny. Yet where someone is going to be killed or kill themself, there is no scrutiny just a bit of paper.

The bill starts off by talking about recognising the right of a person to end their life, confirming the right of a terminally ill person to request assistance from a medically qualified person to voluntarily terminate his life. There is no such right at all. Where is the right? The

---

right does not exist under your code; your code is against that. Unless you have amended it recently, it is still an offence here to attempt suicide. So you do not have a right to have someone kill you. You do not even have the right to kill yourself. You may kill yourself, but people can stop you if they find you. You have no right. The whole bill is flawed by that preamble for a start. It is an outrageous suggestion, that you have that right. You do not. The common law, the international covenants, none of those instruments give anyone the right to kill themselves.

So where does Mr Perron get that from? He gets it from the Victorian Voluntary Euthanasia Society, I suggest, and they are pushing hard. They have a politician who is willing to push their line, their barrow. I do not mean that in an insulting way, because he honestly believes it, I am sure. He is sincere, there is no doubt. But they have not been able to get a Victorian politician to introduce that bill in Victoria. One would think, why not? Because the Victorian politicians do not want to know about it. They have legislated to cover medical treatment. I do not support that legislation the Medical Treatment Act can be abused, too. But perhaps if it is a decision between euthanasia and that, obviously we would support that instead, as the lesser of two evils. Victoria does not want euthanasia, yet these people are trying to push it up here.

If you are going to legalise this, why not legalise the use of heroin and all sorts of cocktails of drugs? It is the same sort of practice abuse of your own body. People say: 'That is outrageous, I do not want that to happen', but morally, when you are prepared to legalise killing yourself, why stop at that? Why stop people illegally gambling? What harm are they doing, except to the revenue? Why stop people drinking and driving? Why should they not have that choice? You say: 'Because the common good, the majority good, is in stopping those things'. And that is why we suggest you should support the common good in the area of euthanasia.

Even though there may be some who cannot be relieved by palliative care, their mental torture does not mean you allow them to kill themselves with a doctor. It might be hard, but all of us have to die some time. We seem to be putting those people who do not want to suffer on a higher pedestal than people who have been prepared to die in wars, the mothers who have been bringing up children and looking after sick relatives, people who show courage. They are pushed down. They have to comply with the homicide laws in every way. Yet those who perhaps lack a bit of courage and I know it must be terrible to suffer a terminal illness, particularly some of the extreme cancers why should we put them on a pedestal and make an exception for them when the consequences are likely to be chaotic?

I think that is about all I wanted to say. I suggest you ignore the fact that the polls do suggest that 70% to 80% of people want it. How educated are those people? How many of them are terminally ill? That should be the real poll among the terminally ill. I suggest that polls that have been taken in nursing homes and among the terminally ill show a vast majority against euthanasia and in favour of being treated. When you get close to the action, when the blowtorch is applied to the belly, it is amazing how you can see what harm an act can do, whereas somebody who is 21 or 25 or 35, who has no real health worries, is not really going to look too far into the future.

11

---

The fact that you have a popular Chief Minister pushing it undoubtedly has some influence on the numbers, but that will change, just as it changed in Washington and in Oregon and in California. There were large majorities in the polls supporting euthanasia, yet when it got to the line it was close, very close. In Oregon, they got over the line; in Washington and California they did not, after an educated campaign.

Thanks very much for listening. I have probably used up most of the time.

**Mr POOLE:** You have, but I think members have a number of questions to ask.. One of the interesting things about this debate is that we all acknowledge that people use selective quotes or selective statistics to promote their own cause. If you read the whole report from the Netherlands, I think you would generally say that it is probably supportive of the current situation in Holland and is written in many respects from that perspective.

**Mr SMITH:** Yes.

**Mr POOLE:** With all the criticisms of the report or of the actual situation in Holland, why has the law not been changed? They appear to be accepting the status quo, which is quoted by various authorities as killing 22 000 people a year etc., etc., by far the biggest percentage of them involuntarily. I appreciate that it does not apply to Marshall Perron's bill, but I am curious why, if it is such a bad thing, the masses, for want of a better word, have not protested.

**Mr SMITH:** In my opinion, the Netherlands is a country that has lost its way in a lot of ways. As I understand it, they have legalised pornography, they have legalised a lot of drug use, they have a very high abortion rate. It is not a country that has stuck by the guns that it had. During the war, for instance, members of the Dutch medical profession risked their lives. Some of them were executed for refusing to follow the Nazi guidelines on killing Jews and things like that. I think they have lost their way. Why have other countries not followed suit? Just because there has not been a revolution, just because there has not been a defeat of government ... I think the Christian Democrats are Christian in name only, largely. The church attendance rate is much lower there than in most European countries, and certainly lower than here. The Catholic church, which is strongly against these things, is very weak in Holland. That was shown by the Pope's intervention to pick bishops from out of insignificant little parishes and making them archbishops, which has caused an enormous backlash in the Dutch Catholic church. I think to some extent that country is just declining in its moral fibre. I cannot think of any other reason.

However I think there is more opposition than is revealed in some of these reports. Dr Karl Gunning is, I think, president of the Dutch Medical League. I gather that he is getting more and more support in the medical profession in opposition to this. The World Health Organisation has been pushing for more palliative care and hospice treatment in Holland. They have rubbished Holland as a bad example of palliative care. They say the reason that patients cannot get it there is that the government is not interested, because they have all these people killing themselves. They do not need to spend that money.

12

---

I wonder if you already have an excellent paper by Dr John Keown on the law and practice of euthanasia in the Netherlands? It was published in the Law Quarterly Review, an eminent English legal journal, in January 1992. He is an eminent academic who spent 2 years going to Holland and interviewing. His paper supports our stand. (*Hands up a copy of Dr Keown's paper.*)

**Mr POOLE:** With regard to the doctors in Victoria who stood up and said: 'We are doing it now', some notable doctors have done the same in the past, I think. Certainly the president, Brendan Nelson, stood up some months ago and said: 'I admit that I have assisted two or three people, but I do not believe the law should be changed.' What is your society's attitude to that sort of situation that without changing the law, doctors have the right to make those decisions? I know legally they do not, of course.

**Mr SMITH:** Dr Nelson as far as I can gather is not talking about deliberate killings. He is saying that he has given high doses of morphine or some other drug to ease pain, and as a consequence they have died. I have heard him say that on occasions. I have heard him on other occasions sound like he has done it deliberately. Any doctor who does that normally should be prosecuted. But we would not support the current group who have admitted it only 8, I think, out of 4000 or 5000 doctors in Victoria because they are trying to abuse the process.

We have urged the medical associations and the Health Departments in our state to police the euthanasia laws, to seek information on what is happening in hospitals. The medical profession is a very closed shop. We have had doctors and nurses give us information about cases, but they do not want to be witnesses because they feel they will be ostracised. We know of a case where a doctor has been ostracised because she complained to the medical superintendent of the hospital about what a senior doctor was doing basically overdosing his patients. It is a very difficult thing, but we think that the law should be policed and enforced. We would not expect many prosecutions, because it is hard to detect without evidence and willing witnesses are very few.

**Mrs BRAHAM:** In your submission you talk about the primary role of the doctor as the healer of the sick. We are talking about cases where there is no cure. How do you see the role of the doctor in those cases?

**Mr SMITH:** Then we would see them as comforting the dying by caring, by drugs if necessary and other ways. That is still acting as someone's healer in the sense of a psychological healer, to help them. That is the real death with dignity, helping people accept that they are going to die and making them as comfortable as possible.

**Mrs BRAHAM:** The doctor obviously cannot always be a healer.

**Mr SMITH:** No, obviously not. Dr Pollard, who has written a book, The Challenge of Euthanasia I assume you have it has worked in that area. He is strong on the point of view that virtually everyone can be comforted and the pain can be reduced to tolerable levels. Part of the problem that a lot of doctors are not properly trained in pain control. That is

something that I hope this committee could recommend. I know you are not authorised to make recommendations, but you are obviously going to have to say something about what you think. Otherwise all you are doing is writing an article for the Women's Weekly or something. There must be some product out of your experience that other members have not had.

**Mr POOLE:** Sure. With regard to that, while we are not going to make recommendations as to whether or not the committee supports the bill, we are going to summarise what we see as the pros and the cons, and also ask questions of the parliament to enable members to fully debate them. That is an area, I would think, that would be a prime candidate as a question to be answered.

**Mr STIRLING:** From your legal background, would it not be better, if it were going to be done at all, to have it in legislation as tightly bound as possible, rather than regulations?

**Mr SMITH:** No. Normally, if it is a piece of driving legislation or drugs or something like that, it is much more easy to control by having specific provisions in an act of parliament, rather than some vague guideline that has no real enforcement provision. But we say that the nature of this conduct that is proposed to be legalised is such that it just cannot be controlled. That is why we say you should go the way that everyone else has gone, every other committee in this country, including the Canberra one that was stacked with people in support, but ultimately came down against euthanasia. There was a bit of a fight at the end, a political fight, but that was their appreciation of the material put before them.

They did go to other legislation, and it may be that you could clarify some of your legislation, your Natural Death Act. You might want to change that to some extent, I don't know. There might be some worth in making the position of relatives clearer. At law they do not really have any status when they give instructions about an incompetent patient. This is not covered by this legislation, but is probably a bigger problem, that some people may not want to be treated but they have never made any document, while others might want to be treated to the very end. Relatives really have no legal say in it.

**Dr LIM:** Mr Smith, you quoted legal precedents and judgments by eminent people. Then you said that in Victoria, what is happening now is applying public pressure on this committee here to come down with some decision to the parliament of the Northern Territory. Perhaps it is the public ethic changing that is not reflected by judges. Perhaps in fact they are doing their own thing in determining cases as they see them, but not reflecting what the public really need and want. If you suggest that the parliament of the Northern Territory is being pressured by the public of Victoria, maybe there is a public movement wanting this change, and legislators should reflect public opinion rather than legal opinion.

**Mr SMITH:** The problem with legislators reflecting public opinion is that it changes. That might be all right if you are dealing with laws to do with dress on beaches or what people can watch at the movies, on television, things like that. But when you are looking at life itself and homicide laws that should continue to protect us, then I suggest that you must be much more careful in changing the laws.

- The fact that 8 doctors in Victoria made a statement does not mean that the public of Victoria want that change. It is just 8 supporters of voluntary euthanasia. If 8 Right to Life doctors came out and said: 'You should prohibit all abortions', I would agree with them, but I would not expect you to change all the law. There is a debate there, and certain decisions have been reached. I do not agree with their enforcement, but nevertheless to some extent judges have reflected what they see as public opinion. Here I think judges are really only holding the line because they cannot see any good reason for change. In abortion law, Judge Levine in NSW basically picked up changes that had occurred in South Australia and England and which have occurred here since, and put them into the common law of NSW or purported to do so and there has been a brawl ever since over that. He obviously was thinking what he thought the public, or some members of the public it might be the more vocal members considered was more politically correct. But this is an area where we do not think political correctness is appropriate.

**Mr POOLE:** Any other questions? All right, thank you very much for appearing today. Very interesting. We wish you an enjoyable time in the Territory and a safe trip home.

**Mr SMITH:** Unfortunately I have got to go back this afternoon because I am in court tomorrow.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 10.25 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives: Right to Life Australia

Ms Margaret Tighe, Chairperson

Dr Robin Bernhoft, Consultant (USA)

**Note:** This is an edited transcript.

**Issued: Wednesday 5 April 1995**

- 1

---

**Mr POOLE:** I call to order this hearing of the Select Committee on Euthanasia and welcome the following witnesses on behalf of Right to Life Australia: Mrs Margaret Tighe, chairperson, and Dr Robin Bernhoft, consultant from the USA, who are appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise you that the committee has authorised that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera or remain confidential. Please advise me now if that is the case.

**Dr BERNHOFT:** No.

**Mr POOLE:** For the Hansard record, please state your full name and the capacity in which you appear today.

**Dr BERNHOFT:** Dr Robin Bernhoft. I am a surgeon from the United States. I represent the International Anti-Euthanasia Taskforce. We were requested to come by Right to Life Australia.

**Mr POOLE:** Thank you. Now, the format that we have been adopting is to allow you to speak to your submission and then we can go into a general questionandanswer situation. We have 45 minutes.

**Dr BERNHOFT:** Rather than rehash my submission, there are a few other issues that I thought would be worth discussing. I wanted to say upfront that I have been asked so many times in the last 18 hours: 'How dare you come here and tell us how to live?' But I am not here to do that. No one, I think, knows better than I that the United States probably does not have a lot of surplus wisdom for export. But we have been engaged in this debate for 4 years now, and we have learned a few things. I was telling the press a few minutes ago, we have an aphorism in the States: 'Even a blind hog can find an acorn occasionally'. We have discovered, I think, a few valid principles. I wanted to address several of those.

First of all, the demographics, at least on the west coast of America, are very similar to my understanding of Australia, where roughly 11% of the population attend some sort of church occasionally. It is a very outdoorsy, essentially pagan-oriented culture which, at least 4 years ago, supported euthanasia to the tune of around 85%. So this is all fairly familiar.

However, the previous speaker's comments about what exactly do those people understand euthanasia to be, and how much have they thought about it, are, I think, extremely well made. As he mentioned, when we engaged in a practical discussion of the issue in Washington and California, even on extremely limited budgets, the people moved against the idea very quickly. Oregon made the mistake of making a religious issue out of it, which [inaudible] would work as well as it would here in the Northern Territory. It is an idiotic strategy and I take no credit for that.

In any case, the tide of public opinion in the States seems to be moving in our direction now. I give several reasons for that. When one does detailed polling, if you start out even now with the question, 'Do you support the idea of euthanasia?', you will get a 60% to 80% number, depending on what part of the country you do it in. Sometimes it is a bit lower than that, 45% maybe. But when you start talking about practical considerations, how you would prevent various abuses some of which I heard discussed here a few minutes ago you discover the support dropping to the 15% to 20% range very quickly. These are people that I refer to as the Hells Angels vote. These are people who want the right, they really do not care who gets hurt in expressing it.

However, the courts have not seen it that way. There are a number of decisions that I think are very relevant. If you want copies of any of this stuff, I would be happy to drum them up for you and send them over. Last year in Rodriguez v. British Columbia a case I was involved in to some extent, since I live only about 80 miles from Vancouver the Canadian Supreme Court ruled that even if a person had a right to deputise somebody else to kill them, but the public good outweighed that right. They gave about 15 pages of potential abuses that they considered very likely.

In my country, although we do not have quite as stellar an emphasis on the public good as the Canadians or you guys have, I suppose, the courts are beginning to come to those same conclusions. Again, for the same reasons, they are not that influenced by public opinion but they are influenced by the World Health Organisation and other groups that have looked at this issue. In the last 6 months, the Supreme Court of the state of Michigan, the Federal District Court in New York City and the Ninth Circuit Court of Appeals in San Francisco, which is on the federal level, just below the Supreme Court, have all essentially confirmed the Canadian Supreme Court decision that the public interest outweighs the personal interest here because of all the problems of actually making this sort of thing controllable.

The question then is, what precisely are they discussing? In that regard, I just received in the mail a few days ago this is an executive summary; if you want the whole 210 pages, again I can do this an extremely interesting document. Governor Mario Cuomo in New York state is a very well-known pro-choice Democrat. About 5 years ago he appointed a commission representing the whole spectrum of belief on this issue, including the founder of the Society for the Right to Die, the leadership of the New York Civil Liberties Union, and a couple of other organisations that have institutional policies in favour of legalisation. As you will see in the executive summary, that committee after taking 4 years of hearings, evidence from which produced this 210page report, agreed unanimously against legalisation. The Society for the Right to Die person still likes the idea, and still thinks that doctors ought to do it on the sly occasionally, but he does not think and the others that are in that philosophical category do not believe that legalisation is appropriate because ...

**Mr POOLE:** Do we have a copy of that report?

**Dr BERNHOFT:** I have just given you the copy of the executive summary.

**Mr POOLE:** No, of the actual report.

3

---

**Dr BERNHOFT:** It will take a little xeroxing but we will ... In any case, to summarise it, they listed a whole series of potential abuses which they considered to outweigh the potential benefits. The first thing that they mention is something that the World Health Organisation and various other health organisations have been very clear about. I gather that is the case here as well, both from World Health and from what I have been reading in the press here in the last couple of weeks and from faxes and so on. The standard of care for terminally ill people is widely inadequate outside of the UK. I trained for a year in London and found a much higher standard of palliative care there than in most parts of the United States and, from what I have read, in Australia as well. The World Health Organisation has argued, and I think quite convincingly these people give you a lot of documentation, which I will supply that given the lag between discoveries regarding pain management, especially in the last 10 years, and their professional application in the training of doctors and nurses to give that sort of care, a great many more people would die from well-intentioned doctors putting them to death because they did not know how to treat terminal pain. I mention in my submission the cases of my brother and a person named Bill Mahoney, which illustrate the mechanisms of that. A great many more people would die from that than would benefit from legalising euthanasia. In fact, in good centres where good palliative care is being done, very, very few people want to die once they have had their pain and depression taken care of.

But the fact is, in both of our countries, pain and depression routinely are not taken care of. And those are the people that are clamouring for the change. World Health and I would agree completely, and this commission also agrees, that the way to solve that problem is not to take those requests at face value and kill the patients, but rather to train doctors and nurses to give the care that we already know how to give.

In the Age, I believe, one of your Melbourne doctors if I am interpreting the press report correctly was quoted as saying and this set off some red lights in my mind, as a cancer surgeon that his patient was not responding to large boluses of morphine and the nurses were afraid to give any more, therefore she should be euthanased. There are several technical problems with that statement that make me think she was not getting 1995 care. First of all, large doses, which are not repeated until the patient requests it, is absolutely not the way to give morphine. What one does Dr Lim, if you are familiar with this? is to try to maintain a standard blood level, from which my brother had the benefit. He had fractures all over the place, in his spine and his ribs, but he was at the Mayo Clinic and they knew how to do that. He was very comfortable and alert. Almost by definition, if this woman was being treated with this bolus technique she would not have been comfortable. The answer to that is not to kill her. The answer is for that doctor to get up to 1995 standard.

In my personal experience, there have been so many people who have been told by well-intentioned and well-respected doctors: 'It's a shame we can't kill you', who then live 3 or 4 or 5 in Bill Mahoney's case 7 more years of enjoyable life. I consider it a personal tragedy for people like that to be put to death prematurely. Again according to World Health and the New York commission and all the research that I have done on this, there are very, very few people whose pain is not treatable. There are some, but not very many a handful, perhaps, in Australia versus thousands of people who would be put to death prematurely by well-intentioned doctors who simply do not know how to treat pain.

4

---

It is even worse for depression. One of these accompanying statements that Margaret has contains some references. There is a New England Journal of Medicine article, 10 October 1991, on the standard of care in depression, written by two psychiatrists at the University of Rochester in New York. This is repeated in the New York state commission report. The two psychiatrists, Conwell and Calne, initially supported the right to die for patients until they started looking at the application. How well since most people who want to die,terminal or otherwise,are depressed, is depression being treated? Their conclusion is that it is hardly ever treated. So they changed their tune, halfway through the article essentially, and said: 'In the current environment, the likelihood of many, many more people dying from psychiatric malpractice than from the exigencies of their underlying disease is considerable.' They decided that since we have not brought doctors up to speed on that issue either, the disadvantages that outweigh the benefits are considerable. This is the kind of rationale that even Choice in Dying is accepting. I think it is something that has to be taken very seriously.

One thing I do not think I addressed in my submission I am a bit jet-lagged at the moment was the question of abandonment. The third major reason that terminally ill people want to die pain and depression are the first two is abandonment. A very glaring case of abandonment occurred in one of the teaching hospitals in Seattle 3 years ago. It illustrates the difficulty of writing safeguards for this kind of legislation. A 22yearold black man with AIDS from IV drug abuse had his first case of pneumonia. It was not an exotic fungal infection, it was just a routine, minor bacterial in the lung. He could have been treated easily with antibiotics. His doctors, however, at this teaching hospital enlightened people, presumably, but their unconscious paternalism is pretty obvious said: 'Goodness me! What kind of quality of life could this guy have? He has to put up with AIDS and racism and poverty etc., etc. It is a terrible shame to give this guy antibiotics.' They did not ask him. They did not ask his mother. They just did not treat him and he died, 22 years old, from his first case of infection. He probably had at least 5 years, maybe 10 years, of good life left.

The Canadians do not have such inequities of distribution of health care as we have in the States, but they are considerable. For example, the infant mortality for Inuit people Eskimos, essentially is 4 times what it is for the white population. For Cree Indians in Ontario, it is 3 times the white population. This is a point that all of these courts have been mentioning, that these people are going to be dying in much larger numbers than those, like my brother, who were fortunate enough to get good care. This is an obscene prospect, in my opinion.

Additionally, the pressure on the elderly, which the World Health Organisation and the New York commission noted, is considerable. In our polls in Washington and California, we found that 80% to 90% of elderly folks feel guilty about using health resources. They feel they are in the way. To pass this kind of legislation and make that a 'choice' for them would put, I think, an unconscionable degree of guilt and psychological pressure on them. Again, I do not think that that is the kind of society we want to be living in.

There is also financial pressure. You guys have a slightly different health care system. I can tell you what is happening in our system, which is pretty disgusting. We have essentially shifted all of the power not to the people, not to the doctors, but to the insurance companies in

---

the United States in the last 24 months. What this means is that insurance companies now call the shots, they determine employment prospects and income prospects for the doctors. If you get booted out of a preferred provider organisation, you may have a problem getting employment in the future. So you are under immense financial pressure to find the cheapest way to deal with patients.

A friend of mine who runs a hospice in San Diego, Dr Laurel Herbst, was telling me that she has been consistently, in the last 2 or 3 years, getting people referred by doctors who have been pressured by insurance companies into not revealing that they had treatable cancer, but sending them straight to the hospice for palliative care. The people were never given a choice. That is obscene. I think it is a potential problem in any health care system that is financially pressured and I think all of our health care systems are, these days.

The Ninth Circuit Court of Appeals decision in San Francisco pointed out and this is well known to attorneys who have looked at informed consent issues and malpractice issues, and I am sure there is substantial literature in Australia on this as well the idea of independent patient choice is something of a myth, because we physicians actually control the board. We give the patients the information that they act on like the patients who are sent to hospice in San Diego, and they have never been told anything else exists. Whether the patients are not told about palliative care that exists because the doctor does not know any better, or because the doctors have financial reason to shunt them off to the side, does not really make any difference. It is not a free choice if it is not an informed choice. I submit that because at the moment our standard of care on pain and depression is so bad, that the average patient is not going to be given a true choice of what is out there for palliative care. The patient who chooses to die in those circumstances is a victim of consumer fraud, in my opinion, in not choosing freely.

I do not know about Australia, but in my country racial issues are a major factor in turning people against euthanasia. I will give you an example. Two years ago the National Institutes of Health pointed out that black men, with insurance, who need heart surgery are only onethird as likely to receive it as white men with insurance. There is no economic difference both groups have insurance. The only difference is race. One-third as likely to be offered heart surgery ... how much more likely is it that they are going to be offered death?

These are the kind of issues we are looking at. Interestingly, one of the reasons I say the tide is turning in our direction in the States, aside from the political results in the courts and the New York commission being unanimous and all that, is media attention. On Sunday night as I was leaving home 60 Minutes, which is a very big news program in the States on CBS, did a special. Initially in January they did a pro-euthanasia program on Measure 16. But on Sunday they did an extraordinarily anti-euthanasia special, on euthanasia generally, because of these kinds of conditions. Once they looked beneath the surface of the Choice rhetoric, and started looking at applications and how well it would actually work in practice, who would benefit not very many who would be hurt many, many people from different categories it changed. That is a very influential program.

Looking at having all the editorial boards in both Washington and California go against euthanasia, looking at what is happening in the polls now that public support is dropping, once people become more sophisticated on this issue, I think you are going to see the same thing here.

Finally, just a couple of comments on the bill itself. The lack of a mandatory psychiatric evaluation in the bill, I think, speaks for itself in the light of what I have already said. Additionally, the fact that any doctor can recommend it, even without any particular specialty knowledge of palliative care, is a very bad idea for the same reason. Additionally, the lack of a waiting period ..In my deposition I mentioned Ann Sires,a patient of whom I took care for several years off and on. Every time Ann was told bad news, she would get profoundly depressed and want to die. At any one of those times, she would have been sucked in by euthanasia had it been offered to her which it would have had to be, at least in our country. All options are, in theory at least, supposed to be presented under informed consent legislation. The lack of a waiting period victimises people like her.

Lack of family notification, I think, victimises a great many people. Then the only witness to what is happening is the physician, essentially, and whatever random people happen to sign the form.

Finally, the lack of any real oversight is very bad. You have this provision of introducing the death certificate and the request to the coroner who then, as far as I read the bill, does not have any power to investigate unless some independent information comes up. There is no public oversight there.

Holland suggests to me that those technical criticisms are probably irrelevant. You are quite correct in saying that the introduction and the last bit of the Remmelink report are quite favourable. But in the middle there is all this dirty linen. I think they thought they would lose it in the 292 pages. In January 1992 this is very flattering the underassistant or something-or-other to the Minister of Health in Holland came to Seattle with a glossy 32page document they had done because of our criticisms of their system. I had never had a government do that for me before, so it was kind of funny. She said: 'None of this involuntary killing is really going on.' I had my copy of the report. I read German Dutch is not that different. I had been through it with a couple of Dutch doctors who illuminated questions that I had. I had my little 'Postit' notes in there so I asked: 'What about this group of 1030 involuntary and non-voluntary?', and she looked a little piqued. Then I asked: 'There are 4841 people here who were involuntarily overdosed with narcotics what about them? What about these 9000 that had their care taken away and died involuntarily etc., etc?' She became very angry and said: In our country, this is just routine medical care'. By this time I had decided that there was no point in being unduly polite, so I said: 'Lady, in this country if you kill somebody against their will, it's pretty damned rude'.

The bottom line on that is that the Remmelink report also points out that only 41% of the doctors are bound by those safeguards. The other 59% just do what they want. 27% admit to having done involuntary euthanasia.

I would finish with the comment of Daniel Callahan[?], who is medical ethicist at the Hastings Institute of New York, that independently, whether or not the Holland experience existed, which it does and it is well documented by the support of government, the doctor/patient relationship is so private that there is no way to control this sort of thing once it is accepted. It is inherently unregulatable. From a logistical standpoint, to see how easy abuse becomes, if at the moment I were to go to one of my hospitals back in Seattle and hang bags of muscle relaxants and barbiturates on somebody, as they do in Holland, there would be a lot of eyebrows going up. The police would be there within 10 minutes. But if that were happening 4 or 5 times a day, nobody would bother looking at the paperwork. That is how the Dutch doctors get away with it.

Bearing in mind that the Dutch doctors, 25 years ago when they first started doing this, had a reputation for being very democratic, very humble, firstnamebasis kind of people, I cannot conceive of a more intense form of paternalism than putting somebody to death because you think it is the right thing to do, involuntarily. I suggest that Lord Acton's maxim, about power corrupting and absolute power corrupting absolutely, probably is the explanation. I hope, for the benefit of people in the Northern Territory, that instead of going in that direction, and not developing palliative care as the Dutch have not, according to World Health, you would go in the direction of requiring doctors to learn how to do this stuff, requiring hospice insurance to be provided either by the state, as in most cases it is already, or by private arrangement requiring nurses to be brought up to speed, getting the education out there to families and other people as to what options really are in existence, so that they are protected as consumers.

That is the direction to go, because the number of people who really cannot be helped is very, very small. At the moment, huge numbers of people are not being helped. Those people are going to die unnecessarily, unless we go in the direction of actually providing them the opportunity to live with dignity instead of dying. Thank you.

**Mr POOLE:** Thank you. I think one of the problems with this debate is that it becomes fairly clouded because people take the extreme examples in support of the particular cause that they are pushing. Even one of the papers here: 'We could just as easily offer assisted suicide to starving Africans'.

**Dr BERNHOFT:** That is not my line.

**Mr POOLE:** No, but it is a line, and I accept the case. Suppose the bill in the Northern Territory covered the areas you have pointed to that is, you had psychiatric opinion, you had the most modern palliative care in the world etc., etc. I am told, and there has been ample public comment, that there are a percentage of people in terminal illness situations for whom you can do virtually nothing as far as pain relief etc. is concerned, or you can take it only to a certain level. There will always be a very small percentage of people whom you cannot really help. Would you then accept ...

---

**Dr BERNHOFT:** I would not, because there is another issue beyond that which I did not discuss. There is a practical issue if you had two routes, learning all this stuff and applying it, or actually just putting people out of their misery. The Dutch have had that option now for 20 years and they have not done it. So whether that would actually be implemented remains to be seen, given human nature.

The other thing that I think is important and needs to be looked at is the teaching content of the law People in Holland, as best as I can tell, are increasingly looking at themselves as disposable goods. For example, there was a ballerina whom Pieter Admiraal put to death 3 or 4 years ago. She was 26 or 29, something like that. She developed arthritis in her toes and she decided to die. He said: 'One doesn't enjoy this kind of thing, but it's her choice'. I think the degradation of respect for people is considerable. Regardless of the availability, I think there is always going to be a disparity between social classes and so on as to how that is applied. So no, I would not ...

**Mr POOLE:** But we already have, in most states in Australia and in the Northern Territory, the Natural Death Act, which allows you basically to say: 'Flick the machine off'.

**Dr BERNHOFT:** That is a big difference. The question of intent is the whole key to the common law approach to criminality. There is a big difference in intent between letting nature take its course and doing something affirmative to knock somebody off very big difference, in my opinion.

**Mr POOLE:** Yes, but we already have a law that allows you to do that, basically.

**Dr BERNHOFT:** Well, shutting off the machine is not ...

**Mr POOLE:** That is fairly affirmative.

**Dr BERNHOFT:** Yes it is, but it is allowing nature to take its course. I think there is a big difference in the intent on the part of the doctor, between giving up in the face of insuperable odds and not continuing to flog somebody, as we say in medicine, versus moving ahead and intending to stop their heart beating, stop their breathing whatever it is, you are killing directly. I think that the criminal law will suffer tremendously if you start losing the concept of intent. The act and the intent are the two keys to the common law, essentially.

**Dr LIM:** There are obviously instances where nothing in palliative care, nothing in surgery or medicine, can help. Take, for instance, laryngeal carcinoma, where a patient literally dies of asphyxia or hypoxia. That could last for several days. In spite of tracheotomies, whatever, you are not going to relieve this patient, because he is slowly going to suffocate to death. How do you handle such an instance, where this person is going to die within a few days, going through quite extreme suffering?

**Dr BERNHOFT:** In our country, grand juries look at the evidence and say: 'Oh well, this happens'. Situations like that have already been dealt with through the grand jury system.

**Dr LIM:** Are you saying that the practitioner, in fact, becomes the advocate for the patient to go to court and say: 'Look, it is time to do something for the patient'? Or do the patient's relatives or the patient himself or herself request that action?

**Dr BERNHOFT:** The old legal axiom that bad cases make bad law, or hard cases make bad law, comes to mind. They try to draw a line, which again is one of the issues that they would look at in this thing. To try to draw a line that incorporates just those people is impossible. So I do not have any answer to that. I think that, inherently, drawing any line beyond what we [inaudible] now, is going to produce problems.

**Dr LIM:** That is the dilemma that some of us face, that ultimately there is a small percentage of people that nothing can help. Is euthanasia for these people then not a very, very justifiable option not treating the suffering of the therapist, but treating the actual suffering of that patient?

**Dr BERNHOFT:** Again, even there you have to look fairly closely. One of the test cases that the Hemlock folks dragged out in our country is LES, which has some similar features with saliva accumulating in the musculature and the pharynx not functioning. But then you get people like some of the hospice folks in London, who claim: 'We actually deal with that very nicely, thank you very much. That's not a problem'. So again, where do you draw the line? I don't think you can draw a line.

**Mr POOLE:** Going back to the original question asked by Dr Lim, you made the statement that grand juries ...

**Dr BERNHOFT:** They may conclude that it is justifiable homicide if the circumstances are sufficiently compelling. That is what they have been doing. I know they think that as far as drawing a line to create assistance to do that ...

**Mr POOLE:** So, basically, despite the law in Oregon and the legal challenge etc., there are situations that are fairly ...

**Dr BERNHOFT:** They are pretty rare.. My contention would be that you cannot draw a law based on those extreme circumstances that is in any way applicable to the rest of the population.

**Mr POOLE:** But there are exceptions to the rule.

**Dr BERNHOFT:** There are always exceptions to everything.

**Mr POOLE:** What do you think about the current debate in Australia ...

**Dr BERNHOFT:** I have read a bit of it in the last few days.

**Mr POOLE:** ... where doctors are springing out of the woodwork saying: 'Well actually, we do it anyway'?

**Dr BERNHOFT:** That is interesting. I mentioned that one of them, when he was talking about a specific patient, set off some alarm bells in my mind as far as quality of care is concerned. It is a general rule in the States that the doctors who are most keen to legalise it are those who have the least to do with terminal patients, or who have a notoriously bad reputation for doing a bad job of it. Whether that would obtain with these guys, I do not know. The reality is that most doctors who actually do terminal care are willing to say: 'Yes, there may be exceptions, but I've been practising for 20 years and I haven't seen any yet'.

**Mrs BRAHAM:** We can make a comparison with abortion, which used to be performed unregulated. We know the harm that was causing. Now that we do have laws to allow it, we know at least that the patient is cared for that there are safeguards. Can we not say, perhaps, that this is happening unregulated ...

**Dr LIM:** Which patient is cared for?

**Mrs TIGHE:** You are talking about abortions.

**Mrs BRAHAM:** Yes, but if we also ...

**Mrs TIGHE:** I would rather that you asked that later when my turn comes.

**Mrs BRAHAM:** ... put the case that it is unregulated now, it is occurring ...

**Dr BERNHOFT:** Let Margaret deal with abortion.

**Mrs BRAHAM:** ... surely, would it not be better to actually legalise it, so that at least we know what is going on? We do not know at the moment, do we?

**Dr BERNHOFT:** There are 2 points there that I think should be made. One of them is that I really think that it is inherently unregulatable, as I said. Secondly, the commonplace aspect of it, which is again a thing that the New York court and the Canadian court addressed, when it becomes commonplace, people will not be subjected to much scrutiny. The potential for abuse becomes much greater. At the moment if you want to knock somebody off, you have to do it in the dead of night when nobody is looking. But if you could write the orders and nobody checks them because it is just routine, then quite to the contrary, I think it would make abuse much worse.

**Mr POOLE:** But you accept that this bill is not discussing involuntary euthanasia? Obviously we are addressing the involuntary issues, and will make comment on that, but ...

**Dr BERNHOFT:** I think that the protections against involuntary euthanasia here are really pretty flimsy, for the reasons that I have mentioned, so I do not think so.

**Mr STIRLING:** The International AntiEuthanasia Taskforce that you represent is there a chapter in Australia or is it States-based?

---

**Dr BERNHOFT:** It is States-based. We have chapters in England and in Holland. Do we have a chapter in Australia?

**Mrs TIGHE:** No, but they communicate with us. We did bring the head of that organisation to Australia towards the end of 1993, because of the bill in the ACT assembly. Mrs Rita Marker you may have heard of her. She wrote that book about Ann Humphrey, the wife of the head of the Hemlock Society, who ended her life. It was called Deadly Compassion. It was on 60 Minutes.

**Dr BERNHOFT:** Ann's experience was an illustration of the kind of psychological pressure that a person can be put under. When she developed breast cancer Derek Humphrey, the leader of the Hemlock Society, dumped her. He left a message on the answering machine saying he could not deal with another wife with cancer and basically hounded her to her death. Whatever one might say about that this is extremely unpleasant material it is an interesting book because it is all very well documented. I can promise you, Derek Humphrey would have sued us a long time ago if it were not well documented.

**Mr POOLE:** Margaret?

**Mrs TIGHE:** Thanks, Mr Poole. A lot of the things that I would say, I guess, Dr Bernhoft has covered and we have said in our submission. I just want to touch on some aspects of the bill firstly, the fact that it is supposed to apply to people with a terminal illness who are likely to die within 12 months. Illnesses which are not treated, because the patient decides that the treatment is unacceptable to him or her, can very quickly become terminal. Say somebody with a bad heart who is feeling depressed and tired of life, somebody with, say, diabetes or a whole host of diseases, a very bad asthmatic their illness can become terminal because they are not accepting treatment. I think that that really does leave it wide open to abuse.

'Likely to die within 12 months' many of us know people who have been told that and some of them are alive today. They are in remission from their condition. Some of them had a wrong diagnosis. I had a very close friend who died of melanoma two years ago. I remember the day that her sister phoned me and said she had 3 months to live. It was a terrible shock to my friend because she was feeling really well at the time. She could not believe that this melanoma had come back after 20 years. She was shell-shocked. She put up a great battle; she really wanted to live. Even if euthanasia had been available to her, she would not have had it. But had it been available and had she been in favour of it, she could easily have allowed it to happen to her. During the 18 months that she lived I might say that at the end of about 12 months the oncologist who was treating her wiped his hands of her and said to her husband: 'I don't know why she's still alive, frankly' she saw a grandchild born whom she had not expected to live to see. But she did, and she saw that little child really growing. There were other events in her life that she was able to enjoy. She had 4 daughters. They were a pretty well-off family, so the daughters had been used to everything going smoothly for them. It was wonderful to see how they rallied around their mother and how it was a great learning experience for them. I am not suggesting that people have to learn at the expense of other's suffering. Nonetheless, that is the reality of life. It was also a learning experience for me, because I saw a lot of her during her illness.

I have another friend who lives just up the street from us. He was diagnosed with cancer and had major surgery about 3 years ago. A year later he was told that things were looking really bad. It had returned. So he had all the usual treatment, chemotherapy and radiotherapy etc. The amazing thing is that he is still alive, he is walking around. He has a tumour in his back which is inoperable, but funnily enough it is coming out instead of going in. His pain is being very well controlled; he sees a pain relief specialist twice a week. He is having enormous doses of morphine, doses that would knock out any one of us, being healthy. During that period, he has seen 2 grandchildren born, he has had numerous pleasant trips and holidays with his wife, he has experienced his daughter's 21st birthday etc. I was having a good talk to him the other day, after all this controversy, and he said: 'You live one day at a time. The other day I had a bad haemorrhage and I had to have a transfusion. I just felt like I wanted to die, but I had the transfusion. In a couple of days I was feeling much better and enjoying life'.

Here is another very telling story. I do think that we can learn a lot from these instances. We have heard a lot about AIDS patients, and we have heard that some of these doctors in Victoria, who have been very vocal, have been ending the lives of AIDS patients. One of the AIDS organisations has issued a suicide manual for sufferers. What they are really doing is playing into the hands of the people who want to discriminate against them. They cannot see that. I remember having a phone call from two people in Sydney, one with AIDS and his partner, saying how difficult it was to get proper treatment. Some hospitals treat them better than others. At a conference on euthanasia that I attended, at the Monash Bioethics Centre just two years ago, a young doctor spoke about an AIDS patient she was treating. Part of the treatment was some tube that apparently removed all the mucus in his lungs. His partner wanted the tube removed. He exerted enormous pressure on the patient to have the tube removed. The doctor said that she finally gave in to his request, although she really felt she was killing the patient. But at the very last moment, the patient said while his partner was out of the room 'I don't want the tube taken out'. He was a dying patient, but he did not want it. He was being subjected to pressure.

Turning to other aspects of the bill, there are going to be a lot of people involved in the dying process, and they will be accomplices in the killing of the patient. For example, the pharmacist who will have to fill out the prescription, and the doctor, of course, and the accompanying doctor who has to agree to the patient being killed. As well as that, the care-giver who might have to help the patient swallow the lethal dose of tablets or whatever. Then there are the relatives who are sitting by. Under the terms of the bill, they will be free from any blame whatsoever.

Dr Bernhoft raises the point that it can be death on request, because on that very day that the patient asks for his or her life to be ended, the doctor can, under the terms of this bill, do so if he is convinced that he or she really means it. The members of the patient's family might not have a clue about it. It could all occur and would be quite within the terms of the law.

The other aspect which is very frightening is that if a patient is physically or emotionally unable to sign the request form, anybody over the age of 18 can do so. I can just visualise somebody who is very elderly and debilitated lying there and someone asking: 'What do you want us to do, grandma? 'Do you want the doctor to he said that he can put you out of your suffering'. The poor old lady shakes her head but somebody else signs the request form.

I think, too, there is a lot to be said about patients feeling that they must get out of the way. There was an interesting report of a survey in the British Medical Journal last October. Two sociologists had conducted a survey of over 2000 people who had been recently bereaved. They asked them about their relatives who had died, and they said that less than 4% of them had requested that they have an early death. The reason given was either real or perceived dependency. I was speaking to a journalist in Adelaide the other day who was dealing with the same issue there. She had interviewed a woman in a hospice with cancer. The reason that the patient had given for wanting to have her life ended early was that she was concerned about her daughter having to come and visit her every day. It was too much for her daughter, she believed.

I do not think that we should pay attention to opinion polls of hale and hearty people walking around in the street. Somebody comes up to them and asks: 'If you are dying and in agony, do you want the doctor to be able to end your life?' 'Oh, yes!' Instead, look at the people in the nursing homes and in the hospices, and even at the figures quoted by Marshall Perron himself in his speech. They came from Dr Roger Hunt, who is one of the most ardent protagonists of euthanasia in Australia today. He said that 6% of patients at his hospice, where I think there would be two types of palliative care, had asked for an early death. Compare that with the hale and hearty people who have responded to newspaper polls.

The other aspect of it is, as Dr Bernhoft said, that when you give people the correct information and you point out the pitfalls of this ... When I was up here recently, I rode in a lot of taxis and the drivers would say: 'What are you up here for, lady?' etc. I would tell them and we would usually have a conversation. As you know, taxi drivers are pop philosophers and usually very accurate at determining the outcome of elections. These were the men or women on the street in Darwin that I was speaking to. You might talk of national samples of so many, but still ... It was very interesting. At first, most of them said: 'Yes, if you want to do it it's your choice.' After I had talked to them and pointed out the pitfalls, I noticed a big change. People are not fully cognisant of the dangers. I think what has happened in the states of Washington and California is that those people were made aware of the dangers and that is why they rejected it. Even in the state of Oregon, it only very narrowly squeaked through.

Finally, it is obvious that there is an Australia-wide push to legalise euthanasia. Blind Freddy and his dog can see that. People ask: 'What are these people doing from Victoria or Sydney or even from America? It's none of their business'. But the people who are pushing it here and I am talking about Dr Helga Kuhse, Prof. Peter Singer, Dr Roger Hunt, I have attended many conferences and heard them speaking, I have debated Peter Singer and Helga Kuhse on a number of occasions I know where they are coming from. The practice of

euthanasia in Holland has had a very deleterious effect upon the rest of the world, and people in other countries are watching what is happening here, to see what is going to happen with your bill. So it is not just the responsibility of the people who live here in the Northern Territory. You have an awesome responsibility to the rest of Australia, and indeed to the rest of the world.

If you lower the barrier on patient killing, giving in to the vocal few and I say they are a few, I am not talking about the people who answer opinion polls like these doctors, over their socalled right to die, you will be denying the right to life of many. They will be the ones who are most vulnerable and least able to speak up for themselves, and that really is the bottom line in this debate.

There are always going to be some patients who will not be able to be helped sufficiently, but they are very much in the minority. If you go down this track, then life becomes even more disposable, and then the economic factor comes into it. Only 2 years ago, we had the economic and planning advisory committee of the federal government issuing a report which expressed concern about the increasing numbers of elderly in Australia. We have a population imbalance. How these people are going to be cared for, and the cost of caring for them, are real problems. In that report there were suggestions that they should be encouraged to sign living wills, look at medical treatment bills, things like that, whereby people can be encouraged to engage in acts of passive euthanasia. It is a very serious social issue, and as I say, one not just for people in the Northern Territory.

Of course they thought that this was a good place to start because you have Marshall Perron, who is a very prominent and very successful politician. It was very unusual that he was able to take up the flag and run with it. Usually, as in South Australia, it is some backbencher who is not going to get into too much trouble with the rest of the party. Anyway he took up the flag and he is running with it. I think they probably thought it would sail through, and we would wake up one morning and say: 'Gosh, look what has happened in Darwin!' as we did about your cyclone or your bombing. Really, as I say, you have an awesome responsibility to the whole of man or womankind to reject this bill. Any questions?

**Mr POOLE:** I think we have pretty well covered the questions we would ask you with your actual submission. I am sure there are a number of items there that the committee will be seeking answers to from the parliament anyway.

---

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 11.25 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Sue Trollope, Assoc Dean of Law, NTU

**Note:** This is an edited transcript.

**Issued: Wednesday 5 April 1995**

**Mr POOLE**: ..I declare open this hearing of the Select Committee on Euthanasia and welcome Ms Sue Trollope, Associate Dean of Law, Northern Territory University, who is appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful.

I also advise that the committee has authorised that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Please advise us now if that is the case.

**Ms TROLLOPE:** No.

**Mr POOLE:** Thank you. For the Hansard record, please state your full name and the capacity in which you appear today.

**Ms TROLLOPE:** My name is Suzanne Frances Trollope and I appear as an interested lawyer in an area of civil rights.

**Mr POOLE:** Thank you, welcome. The format we have adopted so far has been allowing witnesses to say whatever they want to say and then, with your agreement, we go into a questionandanswer situation.

**Ms TROLLOPE:** I may be different from some of the other witnesses because I am not taking a stand either for or against the proposed legislation. What I would like to do for the committee is to take a lawyer's role, in a way. In my view, if we put in place a voluntary euthanasia law, the parameters of that law will be defined by the legislation itself. So what I would like to do is to go through some of the aspects of the legislation.

I think the first aspect that it is necessary to consider is that this is legislation which will confer a particular legal right on a particular group of people. From the legal point of view, you need to consider why you are creating that right for those people, and what that means in terms of other people's rights whether there are other people left out of the equation, and just where that particular right sits generally among the population.

The other aspect, leaving the rights issue aside, is to ask: 'If we put this legislation in place, would it be workable legislation, does it have any defects, does it have any ambiguities, does it have any anomalies?'

I did have the opportunity to hear the last two witnesses, in particular some of Dr Bernhoft's submission. I noted that he talked to some degree about the American medical system and the American legal system. You need to be somewhat cautious when looking at other people's legal systems. While the American system is a common law system, as is Australia's, they have a number of differences. It is not always possible to translate, with authority, what happens in one American legal system into another legal system.

I noted, for example I think in relation to the patients that you raised, Dr Lim that he said: 'The grand jury would find that that was justifiable homicide'. Of course, we do not have grand juries in Australia. The American grand jury system is a system for actually laying charges for serious offences. You do not just get the charge laid and go on for trial as we do in Australia. The indictable offences go before a grand jury and they have the option of saying: 'We do not think it ought to proceed'. That would not translate into the Australian legal system. The Crown, presumably, faced with what appears to be an admitted homicide, would have to lay charges. The case would have to go for trial before an ordinary jury and a judge would be compelled to say: 'Well, ladies and gentlemen, according to the law this person appears to be guilty of that crime'.

**Mr POOLE:** We are very knowledgeable we all watch 'LA Law'.

**Ms TROLLOPE:** Do you? It is very important in legal education to watch 'LA Law'.

**Mrs BRAHAM:** Are you then saying that these doctors that have come out in public in Victoria should by law be charged?

**Ms TROLLOPE:** They certainly risk that. If the Crown Law Department in Victoria decides to proceed with charges, they certainly risk going on trial for [inaudible] homicide charges.

**Dr LIM:** An admission of [inaudible] act, of an illegal act.

**Ms TROLLOPE:** Yes. That is very different, I think, from the grand jury situation. I just wanted to pass on that caution about evidence of other legal systems.

Looking at the provisions of the bill itself, the provision that causes me the most concern, from the 2 aspects that I was addressing, is the grounds under section 6 that is, that the illness has to be causing the patient severe pain or suffering or distress. They are exclusive grounds, so that distress is a ground itself for euthanasia.

I think the first thing is that allowing a person a right to terminate their life for distress is probably not current practice in this country. It does not sit as current practice in our legal system, and it does not sit as current practice, I think, socially or medically. That is not really how we deal with distress. So from a policy point of view, that would be a departure.

I can give 2 illustrations as to how that is inconsistent, both legally and from a policy view. The first thing is that it would create an anomaly if this ground were to stay in the legislation and it were to be passed. The criminal code makes attempted suicide a crime. That provision was actually put into Northern Territory criminal law in 1983, when the criminal code was passed. It is not an anachronism from a previous age, it is not just something that has hung around since the beginning of the century. It was actually inserted into the criminal law of the Northern Territory in 1983.

---

So if this bill were to be passed, you would be creating a situation where a terminally ill patient is able to request that their life be terminated for distress, but an emotionally distressed person who seeks to terminate their life and is unsuccessful in doing so then becomes, in theory, subject to criminal prosecution. In practice, I am not sure that anyone has actually been prosecuted for attempted suicide, and presumably there have been some attempted suicides during the period since 1983. I think that is one anomaly that requires to be addressed and it might, of course, be addressed by removing that provision from the criminal code.

**Mr POOLE:** I think it is probably easier if we occasionally ask you questions on the particular line, rather than wait till the end. Where the bill states under section D, 'the illness is causing the patient severe pain or suffering or distress', if I hear you correctly, to tidy the legislation you would simply remove the 'or' and the 'or' and have, 'the illness is causing the patient severe pain/suffering/distress'?

**Ms TROLLOPE:** Yes, you could do it that way. You could include distress as a ground. I am not sure whether it is necessary to do that. I think it's really deciding whether you think that ...

**Mr POOLE:** Maybe just remove it and then make it pain and suffering ...

**Ms TROLLOPE:** ... pain and suffering are the requisite grounds, or whether you think that in addition to that, distress ought to be a requisite ground.

**Dr LIM:** How do you legally define suffering and distress, though? You can be a very severely depressed patient, to the stage of being suicidal, to the stage of being moribund, literally not being able to do anything at all. Then you would have treatment and get to a stage where you come out of your moribund state into a societal state, and then you get better. Now, how do you define distress and suffering?

**Ms TROLLOPE:** I think that is another of the problems with distress as a ground, that it is a fairly difficult concept to define. I would not like to try to draft a provision to define distress. As you say, some people may be distressed, but their distress is relieved by medication. They may be distressed, but their distress is relieved by support from their family or from their community. So I think it is a difficult ground.

The problem of defining distress would also cause difficulties to a medical practitioner attempting to decide whether a person comes within the framework of the legislation, particularly because very often patients who are severely ill are distressed not only by their own predicament or their own pain, or by dealing with the prospect of their death, but also by the effect on their family. I think that needs to be very carefully considered. If you allow distress as a ground, are you saying it can be the distress that the patient feels because of the burden or distress that they are causing the rest of the family? Again, I think that is a policy issue that needs to be addressed. And for a medical practitioner, I think that it becomes very difficult to administer. Is the patient distressed for himself or herself, or are they experiencing that sort of wider distress?

---

I think the other anomaly moves into this rights area. If you are conferring a right on the terminally ill, what other people might you be leaving out of the equation? I tried to think of the sort of circumstances in which I might personally express a wish to have my life terminated. It seemed to me that there were probably 3 situations where I would feel like that. The first one is the situation which is currently covered by the Natural Death Act. under which people on life support systems can say: 'I don't want to carry on like that please turn the machine off'. The second group, of course, are the terminally ill. The third group, I think, are people who might be described as having competent minds and useless bodies people who have had very severe accidents and remain mentally competent, but in very physically disabled bodies, or people who are suffering from severely debilitating disease, but whose deaths might well be 20 years off.

It seems to me that many people would be extremely distressed by that predicament, very distressed by the prospect of living for 20 years in that state. If you allow distress as a ground for termination for a terminally ill person, I think the question has to be asked: 'Why would you not extend that right to a person who is similarly distressed perhaps even more distressed because there is no shortterm answer to their predicament?' So again, I would say to the committee that that is a policy issue and a legal issue that needs to be addressed.

The other difficulty that I see with the inclusion of distress in the current draft is that there is no requirement for specialised opinion under this legislation. 2 medical practitioners have to be satisfied on reasonable grounds that the patient is suffering from a terminal illness and is likely to die within 12 months as a result of the illness. If you take distress separately from pain and suffering, it seems to me that a doctor might tell a patient who is diagnosed as having a terminal illness: 'This is an illness which will cause you extreme pain and suffering in the end stages', and the patient might say: 'I am so distressed at that prospect that I don't want to get to that stage. I would like to terminate my life now'.

That might be okay if you could be satisfied about the diagnosis and the prognosis, but I think there is some danger here with nonspecialised medical opinion, combined with the range of illnesses which might be described as terminal. There is not just cancer, at which the bill seems fairly obviously directed, but so many diseases which might be terminal: kidney disease, liver disease, heart disease, AIDS. There is such a variety of illnesses which at some point in their duration could be described as terminal.

If there has not been an onset of the severe manifestations of the disease at the time that the patient requests their life be terminated, I think there is that small chance that the diagnosis may be incorrect, that the prognosis may be incorrect. I put that to you, again because I think it is perhaps something which needs at least some refining in terms of the current legislation. I think I have heard the Chief Minister say: 'Most people do hang on to life until it really reaches a point where it is unbearable'. If that is true, then perhaps the legislation ought to be narrowed to make sure that that is the situation that has been ...

**Mr POOLE:** Just so I hear you the right way, basically what you are saying is that if you wanted to narrow the legislation you would narrow the terminal aspects down to the terminal illness at the stage where the pain and the suffering becomes unbearable that is,

instead of saying, 'I'm HIV positive and I know I'm going to be dead in 5 years, according to the medical opinion, so give me the injection now', or 'I've got cancer and I'm going to die within 12 months according to my doctor, so I'll have the pills or the needle or whatever it is', you would see that area being narrowed down to say that you cannot do that until you reach the stage when no medical treatment, no corrective action, can relieve your pain and suffering.

**Ms TROLLOPE:** To some degree, doing that would answer some of the objections that people have about slippery slopes and the dangers in terminating the life of patients whose lives do not need to be terminated. I think it is possible that the legislation could be redrafted to bring about that sort of situation. The Natural Death Act, for example, allows people who have had nothing happen to them at all to say: 'In the event that I'm on a life support machine, I don't want my life sustained in that way'. It seems to me that this could be similarly framed so that a person in the early stages of what is diagnosed as a terminal illness might then express a wish and have that recorded, so that when they reach a point where it is obvious that the disease will take its course and they no longer wish to continue, the request then be activated. That might perhaps provide the sort of safeguards that ...

**Mrs BRAHAM:** We are talking about the terminal stage, really, rather than the terminal disease?

**Ms TROLLOPE:** I guess that's right.

**Dr LIM:** Would you narrow down the 12 months to something like 2 months, 3 months, or how would you define it? The terminal stage could be 5 years it is still terminal.

**Ms TROLLOPE:** I think there is a difficulty with putting mathematical figures into legislation. You could say 12 months, you could say 6 months, you could say 3 months, but I do not think that that provides an adequate answer for patients. I think you would have to redefine it in a way to say when there is an onset of unacceptable pain and suffering.

**Dr LIM:** Take, for instance, a patient with breast carcinoma, still reasonably well, not in pain, living quite well, doing everything that an average person would do. The chances of brain metastases or secondaries in the brain is high if the breast cancer cannot be treated any further. A day may come when she becomes mentally incompetent. She might not die for 12 months, so she is excluded under clause 6 (b). But she can still get several metastases, enough to cause her to be mentally incompetent for longer than 12 months. Now this bill was meant to help her. She is not being helped because of her loss of mental capacity.

**Ms TROLLOPE:** Yes, I agree. I think that is the problem with putting a figure in the legislation. You might have those patients who might quite competently make that request if they knew that they were going to be in that situation, but because you have the time factor on it, they are outside the parameters. That might be something which requires some further attention.

Leaving aside the question of distress now, I think the specialisation issue is perhaps one that requires addressing. Looking at other Northern Territory legislation, I examined the

---

circumstances in which a medical practitioner may terminate a pregnancy. Where the pregnancy is less than 14 weeks, one of the medical practitioners is required to be a gynaecologist or obstetrician. A specialised opinion is required in that situation, that the continuation of the pregnancy will cause more problems for the patient than the termination. The specialty requirement is withdrawn once you have advanced to the next provision of the act, where the pregnancy exceeds 14 weeks but is less than 20 weeks. I guess that could be explained on the basis that as the pregnancy progresses, the time you take to reach that opinion actually compromises the outcome for the patient. So removing the need for a specialist opinion at that time might be justifiable in terms of patient outcome.

It does not seem to me that there is any compromise in patient outcome with requiring specialised opinion for a terminally ill patient who is requesting a termination of life. One of the difficulties, I guess, for the Northern Territory is the lack of specialisation, but I am not sure that reality ought always to influence the refinement of the legislation that you need. If you are putting in place a law, you ought to be satisfying yourself about the parameters of the law itself and not necessarily looking at the reality of the situation.

**Dr LIM:** Would you want the second medical practitioner to be not just a specialist but in fact a specialist in palliative care, or a psychiatrist? Obviously, as we heard earlier today, some specialists do not have a clue about anything but their own little corner of the world, and are not going to give patients appropriate advice. Do we need, then, to say: 'Hang on a minute, we'll find a specialist who really understands the ongoing care of the dying'? Then they can give the appropriate advice.

**Ms TROLLOPE:** Yes, perhaps a palliative care specialist would be the person to make that second opinion. They bring to the discussion, I suppose, not only the medical diagnosis but also the other options that might be available for the patient. Perhaps that is a worthy safeguard in this sort of legislation.

**Dr LIM:** The way I read this bill, the second medical practitioner does not have to concur whether the person can seek euthanasia or not. The second medical practitioner has to confirm that the diagnosis is correct, that the person is going to die within 12 months and that the patient is competent to make the decision for himself or herself. It does not say that the second practitioner needs to support euthanasia at all.

If I am right in that, then I see a scenario where the second medical practitioner can be coerced by the first, who can say: 'Look, this is not an issue of euthanasia for you. Tell me if this person is competent, tell me if this person is going to die in 12 months. Do you agree? Then please sign here. Thank you very much. I've got it I'm off'. Sure, the second practitioner, understanding that this may be a euthanasia issue, may say: 'I am not prepared to take part in this at all'. But if you are the only 2 doctors in the middle of nowhere, and the patient cannot travel to the nearest major centre where there are other doctors to call on, there may be undue pressure placed on the second practitioner to sign the form while still not supporting euthanasia.

**Ms TROLLOPE:** I am not sure that I entirely agree with that. Section 6(k) says, 'the certificate of request has been signed in the presence of the patient and the first medical practitioner by another medical practitioner after that medical practitioner has discussed the case with the first medical practitioner and the patient and is satisfied, on reasonable grounds, that the certificate is in order, that the patient is competent and the patient's decision to end his or her life has been made freely, voluntarily and after due consideration'. I think that that probably places some responsibility on the second medical practitioner to be sure that the patient is aware that this is a voluntary euthanasia decision and that they do understand the full implications of what they are doing.

**Mr POOLE:** And it also says that you must have discussed it with the first medical practitioner and the patient.

**Ms TROLLOPE:** I would think that it is actually fairly well safeguarded.

**Mr POOLE:** What about the question that has been raised with regard to somebody else legally signing the certificate on behalf of a patient who is emotionally incapable of signing for themselves? I do not see that provision anywhere in the bill.

**Ms TROLLOPE:** No, that was in the first draft and was removed from this draft. The only circumstances now are actual physical inability to sign.

Likewise, assistance was initially able to be given in the administration of a substance where the patient was physically or emotionally unable to administer the substance to themselves. The physical or emotional grounds have been withdrawn. But in my opinion that has not altered the definition of 'assist', because it simply allows the medical practitioner to administer the substance to the patient. So presumably they are able to do that when requested on any basis, whether the patient is physically able and emotionally able to do that or not. Perhaps that is a question worth addressing as well whether there is any good reason for allowing medical practitioners to administer a substance where the patient is physically able to administer the substance to themselves.

**Mr POOLE:** That, I suggest, would come down to a definition of how you are going to do it. I guess there are many ways. You could take a .45 and go bang, or you could take some pills, or you could give yourself an injection. But the evidence seems to be that in the case of the lethal injection there are 2 injections: one puts you to sleep and the other one terminates your life.

**Ms TROLLOPE:** Right.

**Mr POOLE:** If you are asleep, it is pretty hard to give yourself the second one.

**Ms TROLLOPE:** One of the things that I had noted was that it is not spelt out in the legislation as to what the form of assistance is, whether it would be by a lethal injection. I assume when we talk about euthanasia we are talking about gentle and easy death not about picking up .45s .

**Mr POOLE:** No, but some people believe that it is simply a matter of giving yourself an injection, which it is not. And I am led to understand that it is not a simple case of taking a couple of tablets and washing them down, either.

**Ms TROLLOPE:** Presumably, though, one could cause death by taking such things as an overdose of barbiturates and that is something which would be permissible ...

**Dr LIM**: Not available in Australia.

**Ms TROLLOPE:** Not available in Australia?

**Dr LIM:** Well, not legally.

**Ms TROLLOPE:** There is no definition of 'substance' in the legislation, and that was something that I wanted to address. That leaves it in the hands of the medical practitioner to determine what is an appropriate substance. It is, of course, not unusual in legislation to put in a schedule of acceptable substances. Perhaps that is a question the committee would like to address. That, I suppose, is an issue for medical witnesses, as to what might be an acceptable range of substances and what might be acceptable practice, and whether that ought to be spelt out in the legislation itself or whether it is something which is kept in the hands of the medical practitioner.

Returning to the specialisation aspect, there is no minimum period of practice required for the medical practitioners. It is, of course, not unusual in Australia for professional people to have certain limitations placed on them early in their career, to control the overenthusiastic or the underexperienced. It seems to me that the way in which this bill is presently framed would actually prevent a professional body from placing that sort of limitation on its own members. Section 17(2) says: 'A professional organisation or association or health care provider shall not subject a person to censure, discipline, suspension, loss of licence, certificate or other authority to practice, loss of privilege, loss of membership or other penalty for anything that, in good faith, was done or refused to be done by the person which may under this act lawfully be done or refused to be done'. It seems to me that that subsection actually places a bar to a medical association saying that only practitioners with, say, 5 years' experience ought to be taking these decisions under [inaudible] the act.

**Dr LIM:** Under the current legislation, any medical practitioner, after having completed a university course and done 1 year of pre-registration, becomes a fully registered practitioner and can perform any act [inaudible] person, as long as there are no consequences. If there are consequences, then the person has to answer to his or her peers and has to demonstrate competency. How do you judge competency on this? The act of euthanasia is the problem, not so much whether the person can do it or not.

**Ms TROLLOPE:** I think that the answer lies in the consequences. As you say, they can do anything provided there are not bad consequences. Well, the consequence here is fairly final.

---

**Mr POOLE:** But it could also be the other way around, of course. If you have an inexperienced medical practitioner administering the thing, the consequence might be that the patient lives.

**Dr LIM:** He would be damaged. Yes, that is true.

**Mr POOLE:** Not given enough, and be comatose or whatever.

**Ms TROLLOPE:** That is another issue that I wanted to raise for your consideration. It might be something that is worth considering as part of the legislation itself.

The only other point I wanted to raise and I think this is somewhat ambiguous in terms of the present legislation is the role of the health care provider. Health care provider is defined in the bill basically to include medical staff, presumably at a hospital or nursing home, but is wide enough to include non-medical staff as well. I think the Chief Minister, in notes that accompanied the legislation, said that that, for example, would allow a pharmacist who prepared the substance for administration to not be civilly or criminally liable for the preparation of the substance. And that indeed is true. It does seem to me, however, on reading the act and really it is a matter of putting together separate sections that the administration of the substance could actually be performed by a health care provider. That is, it could be performed by a nurse ...

**Dr LIM:** A health worker?

**Ms TROLLOPE:** A health worker ...

**Dr LIM:** I just wonder whether a relative or a ...

**Ms TROLLOPE:** ... or a non-medical person. I am not sure about a relative, because it has to be a person whose duties directly or indirectly relate to the care and medical treatment of the patient. So it seems to me that it probably does have to be someone who is actually attached to the institution.

**Dr LIM:** 'Of the patient', not 'of patients'. That does not restrict it to the profession.

**Ms TROLLOPE:** Yes, I would accept that.

**Dr LIM:** So it could be a relative.

**Ms TROLLOPE:** Yes, I would accept that. I think that you have reached that conclusion by reading section 6(n), which says that the medical practitioner himself or herself provides the assistance and/or is and remains present while the assistance is given and until the death of the patient, together with section 13, which provides that any actions taken by a health care provider on the instructions of the medical practitioner are also covered by the immunity provisions of this act. It seems to me if you put those two sections together, that covers the administration of the substance by a person who is not a medical practitioner or, indeed, not even a medical person. If that is the intention of the act, then I think it needs to be more clearly spelt out..

---

They were the only matters that I wanted to raise.

**Mr POOLE** Very interesting.

**Mr STIRLING:** On that question of experience, and length of time as a doctor, I guess there is no certainty in any case that a person would necessarily know what they were doing. Do you think that the bill should stipulate some form of training, so everyone knows what they are doing?

**Ms TROLLOPE:** That is certainly an option, that there be some basic qualification. It might, for example, involve palliative care training, I suppose, so that a medical practitioner who is taking that sort of action does have some knowledge of alternatives. That might be a reasonable safeguard.

**Dr LIM:** I see the kind of practitioner who wishes to take part in this needing some degree of anaesthetic skill. As has been brought up by previous presenters, halfway through the act a person might say: 'I do not want it after all please stop', and you have injected enough of a drug to produce paralysis, perhaps. The doctor would need to be able to institute procedures to recover the patient. [Inaudible] starting to get bigger and bigger now. Where do you stop from there?

**Mr POOLE:** That is why the .45 is easier.

**Dr LIM:** With regard to the right to rescind the request, it is stated in section 8 that a patient can rescind at any time. In fact, as the injection is being given the patient can rescind. It does not say that either one or both doctors can rescind their signatures when they have signed the form. Again, I look at Dr B, the second doctor, who having gone through all the phases of it says: 'Yes, I agree that person wants to be euthanased, has an illness that could terminate life within 12 months and is mentally competent'. For some reason or other, 11 months down the track, Dr B wishes to withdraw his concurrence. This bill does not allow Dr B to withdraw, even if Dr A decides to go along with it. If Dr A withdraws, the patient has picked the wrong doctor. That is really the whole crux of the thing. Perhaps the patient should have assessed the doctor a bit better. Dr A can always withdraw, and the patient is left in the lurch. Dr B has no choice.

**Ms TROLLOPE:** No, except that Dr B's withdrawal would place Dr A in a very difficult position.

**Dr LIM:** But he cannot withdraw.

**Ms TROLLOPE:** If Dr A proceeds to terminate the patient's life and Dr B has said before that that he is no longer of the opinion that this person freely, voluntarily and after due consideration wished to terminate their life, that might well place Dr A outside the immunity provisions of this act.

**Dr LIM:** Yes, but I have the form with 2 signatures on it. There is no provision here to say that Dr B has withdrawn. I have your signature.

---

**Ms TROLLOPE:** I think it is a matter of evidence, though. Even though Dr B's signature is on the form, Dr B could certainly give evidence in a later proceeding that he had informed Dr A, before the patient's life was terminated, that he was no longer of the view that the patient wished to continue with the termination.

**Dr LIM:** Could there be a scenario where Dr B has a fallingout with Dr A, not because of the patient but for any other reason, whether it be a divorce or a partnership breaking up, and decides to cause some mischief? Dr A is put in a really invidious position.

**Ms TROLLOPE:** I quite agree.

**Mrs BRAHAM:** What should the certificate of death say? Should it relate to the fact that the patient died from a lethal injection, or should it say that the patient died from whatever the terminal illness was? Do you think this act puts a different component into what is on the death certificate?

**Ms TROLLOPE:** As a matter of fact, the patient dies from the lethal injection. They do not die from the terminal illness. In my view, that is what the death certificate ought to record.

**Mr POOLE:** Basically, it is a reportable death by reason only of having occurred during an anaesthetic.

**Dr LIM:** How do you ensure the death certificate will be honestly completed?

**Ms TROLLOPE:** You cannot, just in the same way that you cannot ensure what is happening under the present system.

**Mr POOLE:** There does not seem to be anything in the bill that says you cannot, while all the evidence suggests you are going to die within 12 months, request assistance and have the certificates filled in and then say: 'But I'm all right now I want to wait for 6 months'. You could have a situation in which people who have requested and are mentally competent and qualify for all the reasons, as per the act, might put off the timing of their death for such a period that they are no longer mentally competent. Not competent, particularly, to say: 'Hang on, I've changed my mind'. Should there not be a timeframe?

**Ms TROLLOPE:** Yes, that is one way you could address that problem.

**Mr POOLE:** We have already raised the question of the 12month period. I seem to be coming to the idea that that should not occur until you get to the terminal stage, rather than the prospect of the terminal stage down the road.

**Ms TROLLOPE:** That might answer that concern. I think it is a problem. The patient has to make the request while they are competent, but the legislation does not require that they are competent at the time that the termination is carried out. In reality that would seem not a reasonable thing to require anyway, because that is probably the very circumstance in which

---

people do want to have their life terminated, when they have reached a stage where they are no longer competent. It might be safeguarded, as we discussed earlier, by removing the time factor from it and redrafting it to allow the termination to occur when a certain circumstance is reached.

**Mr POOLE:** I do not accept, and I do not think anybody else should accept, that there are hundreds of doctors running around out there saying: 'Let me do it'. I think the natural tendency of most people is to hang on to life as long as they can. If told you have only 12 months to live, all your fantasies could come alive, I guess, and you might say: 'Let's do it all in 12 months'. I think it would be unfortunate if people were making a decision and putting it on hold.

**Mr STIRLING:** Do you see the bill as legally challengeable by people who are not covered, not terminally ill, but who otherwise fit within the parameters of the bill, on grounds of discrimination or by means of any other legislation?

**Ms TROLLOPE:** I had not thought about that. I suppose it is a possibility, because you are not allowed to discriminate against people at state and federal level on the grounds of disability. I really cannot give you an absolute answer. It would require looking at the anti-discrimination legislation to see how it interacts with this legislation.

**Mr POOLE:** We know who we can ask.

**Dr LIM:** The coroner under this bill is basically a registrar. Does the coroner need to be more than a registrar? In fact should every case that is certified as euthanasia be vetted by the coroner to ensure that all terms and all conditions are met?

**Ms TROLLOPE:** It depends on what you are talking about, in terms of vetting. I think it would be very disturbing for the families of patients who have had their life terminated under this system to have evidence given about that in court. I do not think that I could take the view that that is a desirable thing in the circumstances. That is at one end of the scale. At other end of the scale, the coroner might be given the responsibility of simply reviewing the medical records to see whether matters are in order, and having the ability to enquire further if he feels that there is some anomaly.

**Mr POOLE:** All right, everybody happy? Okay. Thank you very much, Sue. Very interesting.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 12.12 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Dawn Lawrie, private citizen

**Note:** This is an edited transcript.

**Issued: Wednesday 12 April 1995**

1

---

- **Mr POOLE:** I call to order this hearing of the Select Committee on Euthanasia and welcome the following witness, Ms Dawn Lawrie, who is appearing to give evidence; other than in exceptional circumstances witnesses appearing before this committee are not required to take an oath or make an affirmation. However I remind you that the information you give to this committee must be truthful. I also advise that the committee is authorised that for purposes of this inquiry, the usual proscription on the disclosure or publication or material placed before the committee by witnesses does not apply.

Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case.

**Ms LAWRIE:** I do not require it to be taken in camera or remain confidential.

**Mr POOLE:** Thank you. For the Hansard record, would you please state your full name and the capacity in which you appear today.

**Ms LAWRIE:** Yes. Alline Dawn Lawrie; A-L-L-I-N-E, private citizen.

**Mr POOLE:** Thank you, Dawn. We propose to follow the procedure that we have adopted so far unless you have any objection, to allow you to talk to your submission and then we could go into a general question and answer situation and might I just ask with your indulgence, whether we could ask you any questions in your capacity not relating to your submission but to other questions with regard to - or we could make arrangements for you to come back and talk to us, in your official capacity.

**Ms LAWRIE:** If you are referring to Sue's closing remarks in the AntiDiscrimination Act, it is just a matter of fact; I can answer that straight forwardly. If other witnesses are raising questions relating to our Act, I would prefer them to be formally referred and we would provide a considered response.

**Mr POOLE:** All right; maybe we will leave it at that.

**Ms LAWRIE:** But I can answer Sue's queries which was looking at the disability provisions in our Act, we call it 'impairment,' there is a selfexecuting exemption under our Act where if something is done in accordance with Northern Territory statutory law regulations, it falls outside the ambit of our Act.

**Mr POOLE:** Thank you; over to you.

**Ms LAWRIE:** Thank you, Mr Chairman. You have received my submission which I believe places my feelings as selfevident. It is always a temptation to respond to some of the concerns which have been previously raised and I did hear Sue's evidence. May I comment on one of her central issues which was the specialist doctrine.

- 2

---

- The need for an obstetrician and gynaecologist in the case of termination of pregnancy was inserted not with the particular wish of the sponsor of the bill but as a compromise to get the legislation passed. I do not think it has been working in the best interests of people who otherwise would be able to take advantage of that legislation because the Northern Territory has few specialists and we may be placed of course in the position where we do in fact have a specialist but they find the particular procedure morally repugnant and refuse to accede to it -and that is their right - but it does not do much for the patient.

This is not a large metropolis with a variety of specialists to whom one can turn, and of course if you think that is severe in Darwin, we have got to look at the rights of people across the Territory, and it becomes progressively more difficult to find the particular specialist, so I am an antispecialist person.

**Mr POOLE:** Yes. Can I make the observation so far as the indication is whether it is right or not is yet to be worked out, that we are talking possibly of 14 or 15 patients in the Northern Territory per annum, and I do not really see that you would end up with a team of people sort of flying around the community; you know, you would do those sort of things probably in the regional centres anyway.

**Ms LAWRIE:** I do not have much more to add, Mr Chairman, because everything I wanted to say I put in my submission. I tend to write in a succinct manner, but I am happy to answer any questions.

**Dr LIM:** Ms Lawrie, you talk about, I think, one section there about interstate and international input into our operations here and it is not really their right if this is for the Territory and nothing else - the jurisdiction I think - and other witnesses we heard today are saying that whatever happens in the Territory is going to affect national thinking, and international thinking and therefore they have every right to provide their input to us and for us to take into consideration their feelings about the issue.

**Ms LAWRIE:** I have said it needs to be put in context, Dr Lim; furthermore the members of parliament of our legislature are elected to govern according to peace and goodwill for the people of the Territory. I do not deny anybody the right to put their point of view wherever they come from, whichever country or whichever jurisdiction within Australia.

But I think that first and foremost, the committee and indeed the legislature has to look at the wishes of the people of the Territory and so other submissions need to be considered in that light. Because of my background, an expolitician, I am very firmly convinced that it is the duty of Northern Territory members of the legislature to act in the best interests of the Territory, first and foremost.

Having said that, the legislature itself cannot pass laws of course which are contrary to Australian law, and that includes international instruments to which we are a signatory, so I do not see that argument as being particularly logical.

- 3

---

- **Mrs BRAHAM:** Can I ask you; you have heard that public good should outweigh individual rights and you mention the rights that people have. How do you see that in the context of the Northern Territory? Should we be concentrating on making our laws to cover the whole of society or should individuals have the right to say, 'Look, minority groups also have rights. Perhaps we should be legislating to cover the good for them.'

It is individual rights versus public life, rights, I suppose.

**Ms LAWRIE:** I have tried to cover that in my statement. The civilised democratic society allows its citizens maximum individual freedom in accordance with laws designed to protect society from cruel, oppressive and/or destructive behaviour.

There is nothing in the legislation which makes this procedure compulsory and while I am aware that that is being referred to as simplistic, I think it needs to be restated.

This is allowing a procedure to be available to those who wish to avail themselves of it and I have gone on to say I see nothing in the proposal which is inimical to the society in which we live. And I stand by that. Much more I cannot offer.

**Mr POOLE:** It would probably be true to say particularly in the Northern Territory and obviously other states in Australia, we regularly pass laws that justify or allow minorities to attain a certain position whether that - I guess the debatable thing is what you are talking about here, you are talking about the minority being the patients who are requesting it, or the minority as seen by public opinion or whatever.

I mean, we take an oath, at any rate, in the Northern Territory to do the best we can for people in the Northern Territory and the wider thing with regards to the rest of Australia I see that as being for other jurisdictions to really make their own comment on.

**Ms LAWRIE:** If you are talking about the rest of the people of the Northern Territory without an individual poll, it is up to individual members to gauge the feeling of their electorates. I mean, I have a feeling that this is supported by the vast majority of people of the Territory but that is my feeling; that is from anecdotal evidence and speaking to people. I cannot possibly put that forward as a fact.

**Mr POOLE:** Yes. There is actually some evidence that you are probably right but of course it is also a conscience vote and it might be a situation whereby MLAs vote according to their own personal conscience rather than the conscience of their constituents.

**Ms LAWRIE:** I appreciate that, and I have turned my attentive mind to it, Mr Chairman, and I do have one problem with that. While noone could be forced to vote I think in a manner which really outrages them, it took my mind back to the allegation of the faceless men in the '50s and the Australian Labor Party, and it was a very destructive debate for the ALP; it was put forward that they were being manipulated by others who were not elected by the people. Now, I think there is an analogy.

- 4

---

- **Mr POOLE:** Yes, true. I guess that is why they call it a conscience vote.

**Dr LIM:** In your ecclesiastical argument, you say you feel strongly that religious groups should not impose their beliefs on you and; the way I understand Australian culture we are based on a JudeoChristian culture from year dot when we first started here.

Would that therefore permeate our thinking up to this very moment, and therefore religious input needs to be considered because of the JudeoChristian culture that Australia has?

**Ms LAWRIE:** Well, the original Australians were not, of course; they had their own spiritual beliefs, the Aboriginal people, and they still hold them very strongly which some may say are animist and their rights have to be respected. Australia has changed dramatically since World War II to a multicultural, pluralist society and people have the absolute right as long as it within the law, to follow their particular faith and indeed, to accept direction from people authorised to give it in their faith.

I do not quarrel with that; in fact, I say I neither trivialise nor dismiss their right to hold strong views on this issue. I accept all that, but I think it is no longer valid to simply say that Australia is a JudaicChristian country; it is a country of many different values. An interesting argument to Dr Lim is that I have spoken to people who are practising Christians who are in favour of - not personally in favour, but they would not impede this legislation coming into being because they say they would be affecting the rights of others.

So the fact that they are committed and practising Christians does not automatically mean that they are against this legislation for others who may wish to take the benefit.

I am a Jew by birth. I am in favour of it.

**Mr STIRLING:** Dawn, the point I raised with Sue I suppose I would like to come back to, that you are right here that the legislation will allow competent adults to end their lives where there is extreme pain and suffering, I think that the bill itself mentions distress; and at least in some cases of extremely disabled people, there are all of those things - all of those things - extreme distress, pain and suffering, daily, with no end in sight, as is the case in the terminally ill.

Is there not a case then, or would you agree with those people, or should it be broadened? It is a very narrow focus.

**Ms LAWRIE:** Yes, it is narrowly focused, and I think that because of the way the bill has been presented with that narrow focus, it should probably be addressed primarily on the narrow focus. There are fairly strong individuals like me in every society who say, 'If this happened to me I would make my own decision and I would have the happy pills and a bottle of vodka and I do not care what you legislate about.' I mean, there are lots of people like me.

- 5

---

- I don't like .45s, I prefer the happy floating away, but one thing that always terrifies me is that it might not work, and there where would I be? Maybe I would be worse off. I mean, that is the other side. I must say that all of my friends and acquaintances feel the same way, that if push came to shove, and certain circumstances were there, we would wish to make our own decisions as to the termination of our life, and resourceful people do it; sometimes unfortunately in appalling circumstances, which makes it more unfortunate for the family. I mean, suicide is not pleasant for the people who are left, particularly when most of the times they do not know why it happened.

But this is not a person being found in the back paddock with a gunshot wound - this is someone probably after discussion with their loved ones, which is the way I would proceed, taking a deliberate decision that enough is enough; the circumstances are outlined in the bill and I have decided to avail myself of this. It is always going to be distressing for the rest of the family but it is far less distressing than a precipitative action.

As to whether it should be extended; the problem I see with that, Mr Stirling, is that I see that as a bit of a red herring to delay a decision on this legislation.

**Mr POOLE:** Well, to be honest, it is not really a matter for discussion for this human element; we are discussing the proposed bill, not an extension of the proposal.

**Ms LAWRIE:** You just said what I feel very quickly.

**Mr STIRLING:** And on the other point then, whether it would be challengable or not by groups that felt they were left out, I think we were in a position of going to write to, is that right?

**Mr POOLE:** We did not ask that formal question.

**Mrs BRAHAM:** I was just going to say; I noticed, when I make a comparison between the Sex Discrimination Act and you talk about the flowon effect and that in actual fact there was not a lot of repercussions as a result of this Act being introduced - would you like .............

**Ms LAWRIE:** Yes, the debate on the Federal Sex Discrimination Bill goes down in history as one of the most divisive and bitter debates. I was going to bring it along for the committee but I mean, it included people saying that children were to be torn from their mothers' breasts and men were to be emasculated, it was really the end of civilisation as we know. That was a tremendously emotional debate and none of that appears to me to have happened.

I mean, a fair and just and equal society is something we all aspire to, and social change - if we are in an evolutionary society, the Federal SDA as we call it, is part of the social change - we should not fear that; this is another part of social change.

**Mr POOLE:** The ice melting on the slippery slope.

- 6

---

- **Mrs BRAHAM:** We see other instances, in divorce, for instance, or in the decriminalisation of homosexuality, I mean, it is all part of those social changes.

**Ms LAWRIE:** Yes, and Murphy's Family Law Act, a lot of the criticism ignores the fact that what he was trying to do was make the law accessible to the people; the law was not for lawyers, it was for people, and he was a very courageous person.

**Mr POOLE:** Thank you very much, Ms Lawrie; good to see you, and we will write to you. Thanks.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 13.10 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative: T I A P (Terminally Ill Act Petition)

Ms Lynda Cracknell

Mr Peter Standish

Mr Hinton Lowe

Mr Andy Chapman

**Note:** This is an edited transcript.

**Issued: Wednesday 5 April 1995**

- 1

---

- **Mr POOLE:** I welcome the following witnesses on behalf of the TIAP, the Terminally Ill Act Petition - Ms Linda Cracknell, Mr Peter Standish, Mr Hinton Lowe, and Mr Andy Chapman, who are appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that the committee is authorised that for the purposes of this inquiry the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply.

Witnesses do have the right to request that their evidence is taken in camera and/or to remain confidential. Could you please advise whether or not that is the case.

**Ms CRACKNELL:** We have no problems about the hearing remaining open, Eric.

**Mr POOLE:** Thank you very much. For the Hansard record, could I please ask you to state your full name and the capacity in which you appear today, and I say that if you are all going to speak, we would like you all to do that, when it comes to your turn to making contributions to the submission.

The format we have adopted to date has been that you make your submission; if acceptable to you then we go into a general question and answer situation.

**Ms CRACKNELL:** That is fine. My name is Lynda Cracknell, and I am here as the convenor of the group known as Operation TIAP.

I hope that you have had a change to read the introduction to our submission.. I realise that you have been flooded with information and you may not have all got to read the full report. The introduction states that we are claiming our right to choose the time of our own death due to terminal illness, and we are advocating on behalf of others who wish to do the same thing.

We do not argue about the choices of people who do not want to avail themselves of those freedoms; we believe that the choices that are presented within the Act accommodate the different views in our community and beliefs, and we respect the different beliefs in our society.

From my point of view, the introduction is summed up in the last paragrah of page 3 where Lord Mustill is quoted as saying:

- *It is important, particularly in the area of criminal law which governs conduct, that society's notions of what is the law and what is right, should coincide. One role of the legislators is to detect any disparity between this notions and to take appropriate actions to close the gap.*
- 2

---

- As members of the Northern Territory Legislative Assembly, I would hope that your focus is on closing that gap which we perceive to exist between the views of our Northern Territory society and the state of the current law.

The advocates of the submission, the people known as Operation TIAP, are a very informal group of Northern Territory residents who have come together to work towards the common goal of having this bill passed in parliament. We are a very diverse group. We are of different ages, background, employment, religions and even politics. Of course, I have not asked everybody, but these things come to light.

Our one goal, regardless of what our personal motivations, is to see the passage of the Act. Some are motivated by personal experiences; some because of our belief in democracy and the need for members of parliament to represent their electorates. As we see it, the electorate view is supportive of the proposed Act.

I will not bore you by going through it in detail. I am sure most of you will either have read it or will have an opportunity to do so before debating the bill in parliament.

On page 6, item 2.3.1 we raise our concerns about the lack of strong Aboriginal representation on our group. We are concerned that the Aboriginal community may be uniformed about the bill and we will certainly do what we can to improve that situation. We also suggest to this committee that there may be opportunities to involve the Aboriginal communities in drafting whatever subsidiary regulations or refinements might be necessary before the bill is passed..

With those few words, I would like to hand over to Andy Chapman. Andy will discuss section 3, which covers the current situation and the arguments for and against.

**Mr CHAPMAN:** My full name is Andrew Louis Chapman, and as Lynda said I am just here to speak to section 3.1 of the submission.

We believe that those who argue for the maintenance of the status quo do so on a number of grounds, the most important of which we have listed here. One of these is the defence or maintenance of the absolute principle of the universal sanctity of human life. There is also the notion of a divine will or a natural order of things against which we as humans should not transgress, in which suffering to some extent is actually good for us in so far as it helps us adapt better to both living and dying.

Another ground for maintaining the status quo is that if once we start killing for kindness, then it is a very easy step to begin killing for other reasons. Therefore under no circumstances should we begin to kill for kindness.

Another justification for maintaining the status quo is that, if it becomes legitimate to kill people for kindness, why should we worry about providing or improving palliative care: 'Let's knock 'em off. Let's not worry about providing palliative care'.

- 3

---

- Let me comment on the first of these, the universal sanctity of human life. We would argue that this principle is not absolute, as was found recently by the legal profession in the United Kingdom. In other words, it is legitimate to place a value on the individual human life. In the case of this bill, it would be I placing a value on my life, in terms of whether I thought it was worth continuing or prolonging under certain circumstances.

As for the question of a divine will or natural order of events; I think we would readily agree that there appears to be a natural order. As to whether there is a divinity behind this natural order, I think we would argue that there is still room for reasonable doubt.

Then there is the question of the kind of suffering which would be of value to me. Suffering has long said to be good for the soul. What is often not clear is just how much suffering would be actually good for my soul, and whose right is it to say just how much suffering is good for my soul. Should my community judge how much suffering would be good for my soul, or should I have the right to judge how much suffering I think is good for my soul?

As for the slippery slope, or the easy progression from killing for kindness to killing for other unkind reasons, we would urge the committee to consider the following.

Must we in order to prevent the wholesale slaughter of the innocent and incapacitated among us, continue to deny the dying the relief from suffering that only death can bring? Does this really have to be the tradeoff? Does it? We would argue that it does not need to be.

Then there is the issue of palliative care in relation to the dying. Some people have sought to link it with the bill. Others think it should be treated as a separate issue. Clearly it is related to care of the dying. We doubt, however, that the passage of this bill would really reduce the human effort which presently goes into the improvement of palliative care.

We would also argue that there often comes a time when the best that palliative care can do for a dying individual is simply not enough. There are some individuals who will say that they have had enough. At present, we might well argue that that individual is at the mercy of the medical profession. Some argue that the business of health today has become such an enormous industry that there are enormous vested interests in the prolongation of human life. Regardless of the cost to the individual or to the community, whether expressed in monetary terms or otherwise, the individual is in fact at the mercy of the medical profession.

I think I have exceeded my time, or I have certainly gone close to it.

**Ms CRACKNELL:** That is fine, Andy. I think your point about the vested interests is very worthy.

I hope that the fact that we are a Northern Territory group is I hope one of our strengths in this matter. A lot of vested interests who are buying into this issue at the moment have nothing to do with the Northern Territory.

- 4

---

- My apologies, Hinton. I will hand over to you to address section 3.2, the benefits of the bill, as we see them.

**Mr POOLE:** Can I just interrupt befpre you start? My understanding was that you had no objection to the media taking some file footage while you are here.

**Ms CRACKNELL:** That is correct, Mr Chairman.

**Mr POOLE:** There is a provision that they cannot utilise live transcripts but can of course ask you questions about your evidence at your convenience at a later stage.

**Mr LOWE:** Thank you, Mr Chairman. I am Hinton Lowe and a member of the executive committee of this group. I am going to speak briefly to section 3.2 of our submission, which relates to the benefits that can flow from the enactment of the bill and the practices it would permit.

The reduction of suffering of patients would be seen as a benefit by many people who are suffering terminal illnesses, reduction of the risks of people attempting as some certainly do to take their own lives, unassisted, and sometimes with very disastrous results, and those attempts do not succeed and I am sure you have heard many cases in these hearings of those sorts of incidents.

Relatives often also suffer great distress, especially at those later stages of an illness when they are aware that there is nothing more they can do in the way of comfort and they see the deterioration of somebody they care for - relatives or partners, spouses - and certainly from my own experience I have been aware of such a time when my mother was ready.

Patients often experience not only excruciating pain but also a loss of dignity. I believe that this is a consideration for many of us, especially where someone deteriorates to such an extent that they are virtually no longer recognisable to others as the same person, and where there is total dependency on the medical system, health professionals and technology. Such a prospect is quite horrific to some of us, certainly to me in particular. I believe that I would choose not to spend very much time in that condition at all.

---

- A further very important benefit that would flow from the bill relates to the considerable evidence that this type of assistance is rendered to people through current medical practice. Much of the evidence concerning this comes from anonymous statistics. I am sure that published statistics have been presented to you and I am certainly not going to go into that. However, a report in the Medical Journal of Australia made reference to research which indicates that many doctors at least known of other doctors who have assisted patients to die. That the events of recent days show is that some doctors are willing to state in public that they done so. One can only wonder at how many other doctors have done the same but are not prepared to take the risk of saying so in public.

---

5

- So a question arises; if this practise is going on, are there some concerns about the relative lack of control and scrutiny, the lack of clarity about what the conditions are under which it is acceptable and permissible? People talk about the slippery slide from this legislation towards other kinds of termination including possibly abuses against the will of the patient, but how much more likely surely is that when we have the present situation in which there are no guidelines, than there is virtually no scrutiny?

Certainly I would suggest that such risks would if anything be reduced by having clarity in the public arena, the public domain, about the conditions under which our society now accepts or approves the practise of assisting patients to die.

I think that is probably enough for me now and I am passing over to Peter.

**Mr STANDISH:** Mr Chairman, Peter Standish, a member of Operation TIAP and I am here to basically go through section 4 where we deal with the extent of the public support for the decriminalisation of voluntary euthanasia.

There have been, as you would be aware, a number of polls conducted over a number of years in the general population; the latest figures that we have from a Newspoll that was taken is appended as part of the document indicates that in a general population - this was taken on a national basis which shows on page 20 of our submission to you - 1994/95 figures taken by Newspoll shows an overwhelming majority in favour, but it also shows the trend of growing support for voluntary euthanasia. You will notice the '95 figures there is greater support, less against, and the unconfirmed percentage also shows a drop so we believe, based on that, based on other research that has been done within the Territory also indicates that there is a great deal of public support for the bill.

We have also heard comments on the lack of surveys being done amongst the medical profession; we have also included here and Hinton referred to it earlier, a synopsis of a survey that was done amongst the Victorian medical profession and we thought it was quite interesting to break it down based on the on the secular and religious views and the religious beliefs of the doctors, so there is quite a large disparity between the answers that came in based on a secular basis compared to those that were answered on a religious basis.

These figures are on page 21; it is also interesting to see the breakdown between the various faiths and then on page 22, comments have also been made of the fact that it is only the younger people who are in favour of euthanasia - as you get older, people will tend to go more against voluntary euthanasia, so on 22, on the results, we have broken down the support and antiside from the medical profession based on their age groups and I think that shows fairly well that there is a support there.

- 6

---

- As Hinton alluded to earlier, the coming public of the medical profession where they are now coming out as individuals and asserting the fact that yes, they have, under current law, committed murder and their feelings are strong enough to come out into the open.

We believe that there is quite a support within the medical profession within the Northern Territory as well for the passage of the bill.

The argument that we placed there before the committee is that we believe that the legislature should reflect the wills and the beliefs of the society which they are representing, and we believe that those polls and things that have been taken indicate that there is a public support for the passage of the bill.

**Ms CRACKNELL:** If you can cover now for us, Hinton, the ethical view, section 5.

**Mr LOWE:** Yes. The main thrust of section 5 is to recognise that there is a diversity, there are differences, different ethical views held by groups of people in our population, that not all people necessarily hold ethical views which most doctors derive from religious belief about the sanctity of life as a foundation of moral decisions, and in fact hold that other foundations of ethical views are more coherent and perhaps more consistent with the realities of contemporary life especially developments in medical science and technology and methods.

Some of those people whether or not they at the same time hold religious views, would rather build their ethical judgments on the principle of the quality of life. There is another ethical principle that is I think highly relevant in this area, and that is the principle of the right of the individual to personal choice in matters of their own life and which are not properly matters for intervention by the state - that is, I suppose, broadly speaking the area of privacy, so that at least these 3 ethical principles are in the area that we are considering.

The humanist ethic to which in fact I subscribe to myself has been I think very well written about by Professor Peter Singer in his book published last year, Rethinking Life and Death, and so I think the committee can if you are interested, refer there to more detail about how that position is argued, and so therefore what its basis is.

However, to come back; the principal thrust of this is that yes, there are these differences with views. I myself hold a humanist ethic, someone else may hold a religionbased sanctity of life ethic, and what we are wanting to say is that neither group should be in the position to compel members of other groups and people who hold differing views to forego the opportunity to make their own choices both in what sort of ethical views they hold and in decisions about how their own life is to be lived and ended.

- 7

---

- We have not here argued in favour or against on any of those ethical views; we would simply want to say that we believe that people who hold differing views should be respected by the law and in a pluralist society, I think we have a strong basis for suggesting that people who do not want to take the opportunities which the bill would afford remain free to do so, but we would suggest that insofar as they would also want to compel others to live by the same principles, they should mind their own business.

**Ms CRACKNELL:** Thank you very much, Hinton. If I may now proceed to a quick summing up and our conclusions in section 6, then we will take more of your questions.

For my summary I would like to just read out some of the highlights through our report and I hope we have convinced you by now that we are just an ordinary bunch of Territorians; we are obviously a lot more eloquent with the pen than we are with the tongue so forgive us our slips here today.

To summarise. We want to advocate respect and responsiveness to the variety of beliefs held in our community in the legislation that governs behaviour in our society. In this respect we believe most strongly that a conscience vote by members should remain true to the representational responsibilities which were undertaken when those members submitted their candidature to the electorate.

The proponents of the submission would be first to insist on the imperatives for improvement in the availability and methods of palliative care We urge the members of the committee to counsel the government to increase its commitment to improving and developing palliative care including research and development and that this recommendation be associated with the passage of Rights of the Terminally Ill Bill.

However, it is unnecessary and undesirable to wait for such developments before passing the bill. We believe there should be minimum delay in providing the benefits of this bill to Territorians.

In our conclusion on section 6, we have said that we believe that there is little sense in the abstract notion of the value of a life which lacks quality or is consumed by suffering, that the person who suffers is the one in a position to make a judgment on whether that life is no longer worth living. In other words, the individual, we believe, is the sovereign authority - not the medical profession, not the individual's family, but the individual, that the respect for the sanctity of life without consideration for its quality or the dignity of the person.............we believe that a person should have the legal right of choice in making the decision to end their suffering.

- 8

---

- It is also very important to note that this group recognises the right of others to hold different views and to make different decisions, and we respect those differences.

So Mr Chairman, and members of the committee, I thank you for your patience in listening to our presentation today, and we would be quite happy to answer any further questions that you may have.

**Mr POOLE:** Thank you very much. Questions. Generally I guess, I can ask you the question - whilst you put a case that the matter really should be decided by the individual as the sovereign authority, and it is not really a question for doctors and other individuals, apart from the person who is affected by the decision, there is fairly rampant public discussion going on at the moment amongst doctors where they have come out of the closet and said, 'I actively have helped people end their lives;' at the moment that is contrary to the laws of the land of course.

Are you satisfied in the bill and that is really what we are looking at today, that there is enough safeguards for people, individuals, to avoid any question of involuntary euthanasia occurring?

**Ms CRACKNELL:** I an answer only as a layperson, Mr Chairman. On my reading of the bill I am left feeling very comfortable that there are safeguards there. I am not a legal expert and I cannot, and I should not comment on whether they are adequate.

I believe they have got to be a lot better than what we have at the moment which is no safeguards and no controls and no legitimacy in the actions that the doctors have taken, so it is to a layperson, one heck of a lot better than what we have got, but I do not believe I can comment on whether it is as good as it could be. If more people can have an opportunity who are more knowledgeable than I am in such matters to look at the details of the bill in terms of whether there is adequate - not just controls, but policing of the controls and so on, then any amendments in those areas which might further improve the bill would be accepted by this group.

**Mr POOLE:** We are of course asking for legal opinions on the bill.

**Ms CRACKNELL:** And I am sure they will be much more expert than ...

**Mr POOLE:** Yes, but I was just wondering whether your organisation had a view with regard to that.

**Ms CRACKNELL:** I think only in as much as I have just given the answer, is that right ...

**Mr CHAPMAN:** We would certainly support the principle, the actual wording of the bill I think - what I would also attack legally is ...

**Mr STANDISH:** Yes to the concept; in other words we cannot be qualified to speak on.

- 9

---

- **Mr LOWE:** And in particular the principle of your decision being one preeminently for and to be taken within the relationship of the patient with his/her doctor; safeguards, yes, but that being the core concept.

**Mr CHAPMAN:** I believe that you had someone from the US - was it yesterday?

**Mr POOLE:** Today.

**Mr CHAPMAN:** Today, who virtually was accusing the medical profession of malpractice in the delivery of elective care. Is that the case?

**Mr POOLE:** I am not sure that he actually said that.

**Dr LIM:** It was just that some doctors are not - most doctors are not well trained enough in palliative care, that is why they are not providing the adequate service. As a consequence patients are suffering needlessly and euthanasia has been used to stop their suffering rather than having adequate modern day palliative care; that is what he was saying.

**Mr POOLE:** Basically saying that there are a lot of doctors in the United States and I am sure the same thing applies here who are not up to date on the most modern practises in palliative care, and I guess you could then go down to the argument - not that Richard would agree - there are some good doctors and some bad doctors.

**Mr ?:** We know that.

**Mr LOWE:** I should ask whether we - it is a view that has been expressed from some members of the profession itself just lately.

**Mr POOLE:** Any further questions?

**Mrs BRAHAM:** I just have to ask Hinton one; I cannot let him get away lightly; but you mention one of your reasons for supporting the bill was the mitigation of distress suffered by relatives. Are you inferring that the bill is there to relieve the suffering of the relatives? If so, I do not think that is a legitimate reason.

**Mr LOWE:** I make a distinction between the purpose of the bill and benefits which flow from it, which are not necessarily its intention. I am referring in that case to a benefit which we can see and may well flow from it, but I understand very well that that is not the purpose of it, and I think it is reasonable to take into account benefits which will flow from something in addition to achieving its intention.

**Mrs BRAHAM:** But it should certainly not be a primary reason ...

**Mr LOWE:** No, therefore it could never be ...

**Mrs BRAHAM:** or a reason for relatives to request that it be undertaken?

- 10

---

- **Mr LOWE:** No, I would certainly be sorry if what is written here would suggest that I believe that; I certainly do not and under no circumstances do I think that these actions should be permitted solely on the basis of the view of relieving the stress of a relative; yes, indeed, there would be many hazards that would come from that.

**Mr STANDISH:** If I could sort of probably expound on what Hinton said and to some extent that is in there on the basis of a personal suffering I went through with my grandmother going back a number of years ago, and the fact that she was suffering which obviously affected the rest of the family and we suffered with her, and I think eventually we found what can only be termed as a bent doctor, and he fulfilled her wishes.

In him doing that, it also relieved our suffering; I think that is probably putting it into context.

**Mr LOWE:** But that was not the principal purpose.

**Mr STANDISH:** No, it was not the principal purpose but it is just a side benefit that occurred when ...

**Mrs BRAHAM:** I just find this an argument perhaps that should not be espoused because it tends to take away from the argument rather than add to it; you know, this saying, 'Look, we are going to feel a lot better when this ...

**Ms CRACKNELL:** I do take your point and yes, I regret that it had that implication.

**Mr POOLE:** I guess it depends on whether you support the bill or not.

**Mr STIRLING:** I want to commend the group for the thoroughness of the submission that you have given us today. I wondered if, in your dealings and talking and research and gathering information and putting your submission together, did you get a fix at all on I guess the numbers of people or the size of the problems throughout the Territory and how widely you think this might be accessed? I am not referring to interstate at all; I am talking of in the Territory.

**Ms CRACKNELL:** I am very pleased to hear that. The extent of support I would say is around the 85, 90% of people who are supportive of seeing this Act passed. The extent of utilisation of the Act I would suggest just on the basis of reasoning and what we have seen and heard in the community would be very, very low. I do not think that you would have hundreds of people every year wishing to exercise their right to die under this Act.

I would suggest that if we are looking at 6 to a dozen, and this is just a personal opinion, we would probably be talking about those numbers because people will in the main want to live, and so we are looking at those people who comply with the conditions of the Act in terms of the longevity of their life, and have reached that point where palliative care is no longer adequate to them for whatever reason. I really do not think the number of people who are going to exercise their choice will be high.

- 11

---

- **Mr LOWE:** However, I think, if I may add to that, that there is benefit to those of us who do think about this possibility, this prospect to many of us, therefore all of us, of at some point in our lives possibly suffering such an illness, that for some of us it would be a great reassurance in our contemplation of that prospect that we would at such a time have such a freedom and for people who do at time experience illness and are uncertain, and need to think about that prospect, I think it is a considerable additional anxiety to know that there may be nothing that they could do.

So I think in that way the issue extends far beyond the actual people who would take the opportunity in any one year to all those many people who face the issue, face up, we might say, to the issue of their own death and the possibilities of experiencing this kind of illness.

**Dr LIM:** Do you feel with palliative care then that to the nth degree if available, would you then say, well maybe euthanasia is not required because we are in control then, because if we are saying that, 'I want to be in control of my dying process because at the end of it all I fear that I am going to be left in the lurch.'

Now, if palliative care was provided in the Northern Territory, does that answer your need?

**Mr LOWE:** No, I do not believe for one minute that any form of palliative care has been developed, and I doubt very much whether it ever will be, which can deal with aspects of suffering such as complete dependency on health professionals and technology to live, to have no control or to put control over one's own - call it bodily functions - to have no capacity to exercise any of one's previous life interests.

These consequences I do not believe can be relieved by palliative care, or relieved except of course for the person to be rendered unconscious of their circumstances.

**Mr STANDISH:** I think, and we have stressed in the report, that palliative care needs to be promoted very heavily and we have urged the committee within our report and I take note of the chairman's comment this morning that the 1996 standard of palliative care - I believe even at that stage with palliative care we are looking at the prolongation of the life with no pain and suffering in the physical sense and hopefully then also in the emotional sense with depression and so forth.

But I think with palliative care, even if we get to that stage of the nth degree, there will still be some cases where palliative care is not successful in fulfilling that role, then need to look at the other stage which Hinton alluded to of the dignity of that person's life even under palliative care, and we believe that the person should have the choice to say, 'Yes, okay, I am living as a vegetable, whatever, but it is not living with dignity, therefore I wish to end my life,' and I believe the person should have that choice.

- 12

---

- **Dr LIM** Are you not judging the quality of that person's life or the quality of your life at that instance, against what you are today? I mean, what you are today is measured against what you might be and the fear of what you might be is the concern. How are you to know that when you are the way you are, that you might say, 'Look hey, hang on a minute, it is not that bad really.'

And therefore, having enacted the law, it is there, not that you need it now, but it might be open to abuse by people who are not ethical enough to ...

**Mr LOWE:** I thought the relevant provision of the bill was that it would be the patient who makes that decision.

**Mr STANDISH:** The individual makes that decision.

**Mr LOWE:** Should I find myself of a different mind than I am today in my expectations, I would simply then not make that choice. The bill provides for that.

**Dr LIM:** Except my closing statement was that, but you then enact a law that is open to abuse by the less scrupulous amongst us.

**Ms CRACKNELL:** In what way, Richard?

**Mr LOWE:** I do not see that the bill is opening opportunities or extending opportunities for people who are unconscionable. I would have thought that by clarifying those circumstances under which a patient may make such a choice and then be assisted, clarify that and bring it into the public arena, given that we know that this goes on already is going, if anything, to reduce those risks. That would be my view on that.

**Mr CHAPMAN:** The present situation is not open to abuse as Brian Pollard, whose book you might have read, he wrote a book called, Should We Kill the Dying; he claims that on the basis of his experience the greatest fear among many of the dying is just that - that their lives will be prolonged unnecessarily - not in their interests, but in the interest of the business of health, in big business interests - manufacture of drugs and the provision of services.

**Dr LIM:** Doctors and pharmaceutical companies, they encourage the prolongation of life to generate business.

**Mr LOWE?:** Technological development, including the development of drugs.

**Mr STANDISH?:** Certainly they have a vested interest, financially.

**Mr CHAPMAN:** Our health industry is so enormous that like any other big business, it is open to excess and abuse.

- 13

---

- **Ms CRACKNELL:** I hope that the committee does temper its considerations you know, with that knowledge, that a lot of the people who are addressing it do have vested interests of one sort or another, not just the medical profession only - it is not a shot at you, Richard, and we like to think that our strength is the fact that we do not have any vested interests, that we are just a bunch of Territorians and we hope that our submission will have extra credibility in your eyes for that very reason.

**Mr POOLE:** I would suggest to you that other people of course will take an opposite view.

**Mr STANDISH:** That we are just downtown hicks? Yes.

**Mr POOLE:** Whatever the reason; I mean, at the end of the day ...

**Mr STANDISH:** The socalled experts.

**Mr POOLE:** ... there are people arguing from both ends of the spectrum, and I guess I should have posed the question to you; if all the things seen by some people to be loopholes in the Act or ways and means to enable people to do unscrupulous things as doctors or assisting, or whatever, if all those things were addressed and the Act was a really tight Act, I guess it would come down to a choice between the sanctity of life and the concept of freedom of choice.

I presume that you would go for the freedom of choice?

**Ms CRACKNELL:** Yes.

**Mr LOWE:** I certainly would.

**Mr STANDISH:** One of the things that Dr Lim put forward there of the medical profession thing, and it was something that was mentioned this morning of the sanctity of the relationship between the doctor and patient and I think everybody will agree that is a very precious relationship, and I would argue that the duty of the doctor is to care for the patient, full stop.

Now, if the patient is in that situation where he has made a decision to end his life and wished to die, surely that relationship is at the point where the doctor should feel sympathetic to the patient, in his duty of care to the patient.

**Mr POOLE:** That is a bit of a horrible question. I do not think the committee is in a position to answer that. I guess we would like to agree with you or some of us might, but others, and doctors, might not.

**Mr LOWE:** However the bill makes provision for that and protects - if anything it protects that relationship rather than intruding into it.

- 14

---

- **Dr LIM:** We have discussed Aboriginal views; have you sought any at all or you have not been able to get any?

**Ms CRACKNELL:** We have had some input from some sources - Peter, you might like to speak to that.

**Mr STANDISH:** It has been a difficult situation; we tried through the media to get some information out. We had some response come back; some of it has been a situation of, yes we would like to help but; we have respected those views and it is one of the things that has concerned us to we believe, have a fully balanced representation from the people in the Territory, the committee in the Territory needs to be in a position to get the views from the outer lying communities and again to get their balanced views.

We make illusion in the report to one situation where I was advised by a person that, yes I would love to help etcetera etcetera but if I am seen to help and distribute the stuff I will be put off that community. And we have alluded to the fact there of misinformation type thing, and I said, you know, can I go public and mention names etcetera? And I was told, please don't because then I will be off it as well.

So there is that perception - that has come from a couple of sources, and it is one of the things that I suppose it does upset us in that the religious perception being foisted upon these two communities and not being brought into an open discussion.

**Mr POOLE:** Thank you very much for your time and effort in making your submission and appearing in front of us today.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 14.10 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Janie Mason, private citizen (Senior Lecturer, Nursing & Health Sciences, NTU)

**Note:** This is an edited transcript.

**Issued: Wednesday 5 April 1995**

- 1

---

**Mr POOLE:** I call to order this hearing on the Select Committee on euthanasia and welcome the following witness, Ms E.A.Janie Mason, senior lecturer in nursing and health sciences at the Northern Territory University who is appearing to give evidence.

Other than in exceptional circumstances witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that information you give to this committee must be truthful. I also advise you that the committee has authorised that for the purposes of this inquiry, the usual prescription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence is taken in camera and/or remain confidential. Could you advise us if that is the case?

**Ms MASON:** It doesn't have to be in camera.

**Mr POOLE:** Thank you. For the Hansard record, would you please state your full name and the capacity in which you appear today?

**Ms MASON:** My legal name is Elizabeth Ann Mason. My normal signature is Janie.

**Mr POOLE:** Welcome.

**Ms MASON:** And I appear as a private individual but obviously my professional background is a large part of why I feel that I wanted to appear. So I don't represent the university and I do not represent the School of Health Sciences.

**Mr POOLE:** Okay, fine. Thank you for appearing, Janie, and welcome. The format we've adopted so far is to allow people to talk to or make whatever submission they want to make, then we go into general question and answer, if that's agreeable with you. Over to you then.

**Ms MASON:** I think perhaps I should give a little bit of personal background. I come from an angloCatholic family and I had a childhood experience, a long term childhood experience, of a dying uncle who lived with us throughout my childhood and he suffered from what is now known as multiple sclerosis. It was a heavy trauma on my parents. He lived with us for nearly 15 years. I do believe that the weight of his illness was responsible for my mother's appalling obstetric history and he then, when I was about 15 or 16, was transferred to a hospice which very kindly took him although he was not going to be dead within the required period.

He was, contrary to the usual, the average picture. He was contrary to that picture in that he took very much longer to die from his disease than is typical and he was in there for many years and we hated visiting him, just hated it, because even when he could only point to letters on the alphabet, he said he wanted to die. He said it for years. So, that's fairly heavily influenced me.

---

My parents, particularly my father, is a member of the New South Wales Euthanasia Society and spends an inordinate amount of time, in my view, telling me about the latest changes to his will and you know, when he goes to surgery - some recent surgery, I got urgent messages to come down and special anaesthetic permission forms were designed whereby I was to be the next of kin, not my mother, and I was to be responsible for ensuring that the equipment was turned off if he stayed too long on supportive prolonging devices.

So, then there's my professional experience and I must say that in my experience, euthanasia does occur. It occurs fairly regularly and I have participated in it. It's not without thought and it wasn't sometimes without tears and I won't bore you with some of the cases that immediately spring to mind.

I went into teaching in the late 70s and my area is actually mainly in community and cross-cultural teaching and social aspects of health. That means, because we're jacks of all trade around our way, that at times I teach the bioethics unit. In teaching the bioethics unit, it has been an opportunity for me to maintain or see some of the current literature but it didn't form my opinions. My opinions came from my family background and from my practice.

I actually am very pleased that this bill is proposed. I think it brings out of the hidden corners, the opportunity to have a discourse about euthanasia. I think that's terribly important. It's occurring and we should be monitoring what's going on and at least in a small way, if this bill did get through, there would be some opportunity to monitor what's going on instead of having it hidden.

I do not believe palliative care with all the modern drugs and devices is sufficient in every case. Whether we are talking about intractable pain or whether we're talking about people who are unhappy to compromise with a lifestyle they find unsatisfactory, I do not believe palliative care is 100% the answer.

I don't believe that having a bill, an act in place, even such a limited one as this will open the doors to shonky practice. I think shonky practice is there right now because it's going on when it's actually against the law. So, I don't think it creates any more opportunity for misuse of the system than is already there and I think that if you had an act where it's in place, it would be monitoring. There would be a monitoring of what's happening. It's not monitored now.

So that's why I support this bill very strongly although I feel it has a couple of really major defects. The first major defect is that it neglects the people like my uncle. It omits - I appreciate it is only, if you like, a fishing expedition and so it's been made very narrow to see where things might go and start an open debate, perhaps that's another reason. So, from that point of view, it's a good thing. But from the point of view of the other major category of people who sometimes want to make this decision, it neglects them. It neglects people like my uncle who took an awful long time to die in a very unhappy way of dying.

---

It neglects the people who find themselves trapped in bodies where the life - they cannot learn to live with the compromise of the new body that they've got. It neglects the people who know that they are heading towards a situation which is unbearable to think about where they lose their abilities to think as human beings. You know, the classic ones; altzeimers or senile dementia and so on. It neglects those people. I find that a really disturbing omission because people can live years as quadriplegics and paraplegics and still 5, 6 years down the track say, 'Look, I've really made up my mind, I still want to go.' The evidence is there. There are the classic cases where people have begged, years down the track, to be released. They're not suffering pain, they're just suffering a lifestyle that they just can't bear. There was a classic one with an Australian ski champion that keeps getting quoted for that example. So I think that's a major omission.

The other major weakness to me is, and I will leave - I see you had Sue ...

**Mr POOLE:** Trollope.

**Ms MASON:** ... Trollope, yes, earlier and so I feel sure that she said many of the things that she said to a seminar recently that Marshall Perron was at that was run by the College of Nursing. So, I'll leave out some of the things she said but one of the things that I'd like to raise is the power of the medical professional to block patients to this right if the act does get through.

In the past - and probably still currently for all I know - in the past, there's been plenty of evidence to show that where a particular practice is legal yet it is contrary to the particular medical practitioners beliefs, be they religious or otherwise, that medical practitioner has the power of that relationship to block that patient's access to a treatment that they're entitled to. Now, the obvious example I'm talking about is, of course, termination of pregnancy and this has occurred. It's particularly likely to occur in small towns.

Now, in the act there is no provision to - I know that the patient technically has the right to ask for a referral but I have seen patients asking for referrals and I have seen them blocked. I just would suggest that the act perhaps - the bill, sorry, the bill needs some identification of this as an issue whereby there is some direction or encouragement that if a practitioner, be they nursing or doctor or whatever, has a difficulty with this concept, they should have a legal obligation to make sure that the patient is referred to someone else and I regard that as a second major fault in the bill. I won't go on about assisting suicides or failed suicide sort of arguments. I think Sue probably did that very well.

They are actually the major points I wanted to make.

**Mr POOLE:** Very interesting. Now, I don't want to completely focus on some of the comments you made when you started your own comments, but you said that you'd helped or assisted in some cases of euthanasia. Can I ask you how many?

**Ms MASON:** It would be very difficult to tell now. I mean, sometimes it wasn't ...

---

**Mr POOLE:** I mean, are you talking sort of once or twice or are you talking about ...

**Ms MASON:** Oh no, more than that.

**Mr POOLE:** In your experience, and I appreciate looking at your background that - and I might be incorrect the way I've read it - but you actually haven't worked as a nurse for some time, is that right?

**Ms MASON:** I worked at the hospital. I ceased working at the hospital in 1980. But I still go into the hospital ...

**Mr POOLE:** Oh yeah, sure.

**Ms MASON:** ... and I do ...

**Mr POOLE:** I just wanted to make that point that you're not currently working there.

**Ms MASON:** Yes, we have to do 2 weeks practical upgrade a year.

**Mr POOLE:** And I would presume from your background that you mix a lot with the nursing profession, probably the hospital staff, etcetera?

**Ms MASON:** That's right, and my students, of course, are from there.

**Mr POOLE:** Do you have any general knowledge or do you believe the practice is still reasonably widespread in the Northern Territory.

**Ms MASON:** Well, you teach bioethics and you know, social issues of health-type units and you have in your class a large number of people and the majority of students I teach are actually registered nurses. Only the minority are the pre-registration people and from the discussion in class tutorials, yes, it's still going on.

**Dr LIM:** Could I follow up on that question?

**Mr POOLE:** Sure.

**Dr LIM:** Are you talking about nurses or medical practitioners actually giving lethal doses of medication or are you talking about the omission of particular acts or switching off of respirators at anybody's instruction? I mean, there is a distinction ...

**Ms MASON:** Well, the whole lot and ...

**Dr LIM:** ... well, I need to - it's not clear in my head and I just need to make a distinction between one and the other because obviously there's been talk about - one is the intent - the intents do not - to continue with extraordinary measures versus the actual performing of an act to terminate that person's life. Now, I think ...

---

**Mr POOLE:** Richard, can I - sorry to interrupt you. I just don't want to take us down a track or go down a track that clouds the job that we've got to do today and you know, I have the attitude to these sort of types of questions that we deliberately are not being too specific about it.

**Dr LIM:** Well, when a witness tells me that 'I've done this' I need to understand what is being done, active or passive.

**Ms MASON:** I can answer quite simply. Look, really I have participated in and I know that my students, some of them, still participate in withdrawal of treatment so that you don't have heroic measures. I also know that some of them are participating in, if you like, overgenerous drug regimes and non-insertion of naso-gastric feeding, that kind of thing. Does that answer your question?

**Dr LIM:** Yes, that answers my question.

**Ms MASON:** Or allowing a urinary catheter not to be replaced and thus, the skin breakdown also compiles the issues or the things causing death. So I do know the difference between prolonging and active participation and I say that it is going on, both.

**Ms BRAHAM:** Can I perhaps ask you, does the act satisfy you as regards the immunity of the health care provider meaning a variety of non - not doctors, you know, yourself as the nurse ...

**Ms MASON:** I think one of the things that's important in the debate rather than the act, that the act should be based on the discourse that's around it. One of the things that is ignored is that even though the act is quite specific between doctor and patient and 2 doctors, you know, so one select group of professionals, it must have a significance for every health practitioner and most particularly the one who is with the patient 24 hours a day and I don't think anyone's really addressed or started to discuss what this act - bill, if this bill went through could mean to the day-to-day practice because it won't just change the practice for a medical practitioner, it has to change the practice and thinking of every health professional and particularly the one whose with them 24 hours a day.

I would have liked to have seen some identification of the nurse having a role in this. I'm not - I don't mean necessarily, you know, being the final participant but I do think that there are - I believe, there is more to this activity than just between doctor and patient. I mean, in the past and still today, if a nurse speaks out of turn, she can be in real strife. So, for example, you know, the patient comes to you with a finger going gangrenous, it's been poorly sutured up, and you say, 'Goodness me, did you go to the doctor?' 'Yes, he said it was going to be okay' and I say, 'Well, look I haven't got my name tag on here but I do think you should go and find another doctor, but I didn't say that, please.' You know, what I'm trying to say is we don't have that protection in our system because of the power relations and I would have liked a little more identification for that but I appreciate, it's not something that's easy to put in an act but at least at the discussion level, we should be starting to, say it became an act, we should be starting to identify these issues and how it would inflict on our practice because it will inflict on nurses' practices.

6

---

**Mr POOLE:** I think it is covered in the act in such that they name, for want of a better word, health care provider.

**Ms MASON:** Yes, it embraces the lot.

**Ms BRAHAM:** Yes, yeah. And when you say you think it's going to change the climate in which they work, this has also been mentioned to me, that more people who are looking after people in nursing homes who are not happy, people in the community health work who visit the homes regularly, is it going to have a detrimental effect upon their role with these patients?

**Ms MASON:** Well, there might be a little bit more debate in the open about what's going on in terminal care places. I mean, I don't know if you appreciate, but something like 50% of the health dollar goes on people who will be dead in 12 months and yet you can't get a decent water supply at somewhere like Hermannsburg and they're all under 5 ending up with stones in their kidneys. Those kind of things, I mean, by the way, but for a number of years we had stones in the kidneys of under 5s which should not occur in children that age without congenital defects. Now, it's because the water supply was so thick with solids.

Now, that's real health care to me and yet we're spending half our dollar on the person who is dead within 12 months. I mean, I find that an appalling statistic.

So, I think that maybe in relation to people who are in terminal care, we might have a little bit more open discussion about what we're doing in some of those places. I mean, has anyone discussed with some of those patients about their gastroscopy tubes as they become ever more crunched up in, you know, crippled positions? I mean, has anyone discussed that kind of lifesaving device? Has anyone thought about it? Should we have put that gastrostomy tube in?

**Ms BRAHAM:** So you're really talking about better education of health professionals?

**Ms MASON:** Yes, I would hope that there be more debate go on. If you start to have - it's a bit like the Affirmative Action Act, you know, for all its defects at least it got a very big debate going and it started to change quite a bit of the climate around us. You know, do you see what I'm getting at? I sometimes think acts or law is about education more than enforcement.

**Mr STIRLING:** Janie, opponents of the bill as it stands suggest that often a patient will say they want to die but they're acting from a state of depression at that time and there's not enough - or there's no safeguard in the bill as it stands to ensure that that's not the case. Would you have a view on that or response to that?

7

---

**Ms MASON:** I think that those mechanisms can be strengthened if you want to but I do have a view on it. I mean, there's also a fair bit of evidence around about people who have had some highly questionable heroic treatments done on them and who have even been through ethics committees and the ethics committees have approved what's been done with the proviso that if the patient wants to turn the particular device off or the drug treatment off or whatever, they should be allowed to.

Now, what happens is - fairly typically, that everyone decides the patient's depressed and stops them from turning off the drugs or the machine. Now, that's well documented and at the same time when people - patients say, 'Look, I do want to die' next thing, they're into the psychiatrist's so fast being labelled as a nut case.

I mean, the same with practitioners when they express difficulties about such things say, like terminations, there's evidence that staff who've had difficulty about termination of pregnancy have, because they've been in conflict with maybe the hospital policy or they haven't been allowed to express - to truly express an opportunity to go somewhere else and not practice in that type of care, have been referred by their management, by their employer to psychiatrists. It's a fairly powerful relationship. There's a very strong hierarchy, very high authoritarian in hospital systems and you know, that does happen. So I am very cynical about patients just being depressed temporarily. I think there's a fair bit of evidence to suggest that it's an excuse used not to allow the patient to do what they want and I'm talking about some of the extreme cases which are all well documented but there are others. But the extreme cases well documented are the initial heart pumps, people going on to heart pumps and they just kept getting documented as being depressed and not allowed to turn it off.

**Dr LIM:** Mr Chairman, one question.

**Mr POOLE:** Sure.

**Dr LIM:** You mentioned the business about the legal obligation to refer a patient if a particular practitioner is not keen to participate in the process. In fact, it was in the first draft of the bill which has subsequently been removed ...

**Ms MASON:** So Marshall told us.

**Dr LIM:** Yes. Now, why do you feel that there must be a legal obligation for a person who refuses to participate to, in fact, be coerced into participation because by referring the patient on to somebody else, it is in fact participation whether you like it or not?

**Ms MASON:** Well, that's an argument from your perspective and I won't accept it because if you say that the patient is legally going to have his right of choice, you're not allowing them that legal right of choice if the doctor has the power to refuse a referral. I mean, are we going to give these people a legal right or not? If we're going to give it to them with this act, the person who denies them that referral is denying them their right.

**Dr LIM:** It could be that you agree to another doctor of your own accord ...

---

**Ms MASON:** Well, that can be very difficult for patients and I do feel that the medical professional is not fully cognisant of how difficult it can be for patients to challenge their doctor and say, 'Well look, I actually don't agree, you know, I would like a referral' and if the doctor indicates, 'I don't want to refer you' it can be very difficult for the patient to persist.

Now, they can withdraw and say, 'All right, I'll go and find another doctor' but there's a fair few social pressures against them and the evidence is quite strong that they'll feel intimidated and they won't pursue seeking another doctor.

**Mr POOLE:** All right, any ...

**Mr STIRLING:** Yes. I appreciate you're not as close to the situation, you know, after 80 but you're obviously - you still move in those circles - would you have a view on how many people just might access - might utilise this legislation from within the Northern Territory in a year?

**Ms MASON:** I can't comment on doctors because I don't have medical students...

**Mr STIRLING:** No, on patients.

**Ms MASON: ...** but I have the odd physiotherapist and occupational therapists and pharmacists and certainly amongst the nurses, it's very strong, I would suggest, in support. Certainly, it seems to be in my classes not that I run - I don't think that's my right. That would be intrusive. I don't run a questionnaire on them but there seems to be strong support amongst the health professionals. Amongst patients, I can't comment. I'm not close enough to patients these days. I'm only closer to people in communities and I don't have the right because I'm not employed by the health agencies to really find out what's going on.

I see things that I find very disturbing. People who are transferred to hospitals without discussion of their options put on to kidney machines and you know, several weeks down the track they still aren't aware that they'll never go home again.

Now, if it was ever discussed with that family, is it possible that that family might have opted for the patient to die from uraemia which is actually not an unpleasant death for the customer, it's not pleasant for the people watching, it's a bit smelly, but the patients who are pulled out of uraemia have told me that it was like when you're on a bit of morphine, it's a bit euphoric. So, it's not an unpleasant death and maybe they might've preferred that death.

I would suggest that we're not doing enough to discuss those sort of options with people and I mean, should you put every single person on a kidney machine? I mean, should you offer them the option? I mean, some of the paraplegics we've had around Darwin Hospital in the past, before Chan Park opened, have been very unhappy people who would have much preferred to have been home maybe dying that bit quicker than being kept alive and their skin kept beautiful in Darwin Hospital.

---

I don't think you've got a cast of thousands that we're talking about but I do think you've got some people who would rather die at home even if that's the shorter life and some people who would rather die with a bit of help than go through the agony of the tail end and that's another point. We have an awful track record about pain relief. It's got worse in my view. We are not relieving pain well. There's too much fear of drug addiction. They're all running around scared about giving out morphine or whatever the current analgesia is and then they frighten the patient who is terminally ill.

My hairdresser just died recently and she was always being frightened by both professionals and relatives about, 'What if you become an addict?' What the hell did it matter? She had secondaries all over the place and eventually she died of secondaries in the brain and she suffered appalling pain. Now, all these people were frightening her about drug addiction. Goodness me. I think we've got an appalling attitude to pain relief these days and that applies to all practitioners, nurses and doctors. I don't think we're giving enough pain relief.

**Mr STIRLING:** I'd like to thank Janie for her honest appraisal of the situation, very interesting.

**Ms MASON:** Very up front.

**Mr POOLE:** Thank you. You know, for the later stage, if you want to communicate with the committee, please feel free to do so.

**Ms MASON:** Thank you.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 14.48 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr Jim Burrow, private citizen (Senior Specialist Physician, Darwin)

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

---

**Mr POOLE:** I welcome Mr Jim Burrow, senior specialist physician in Darwin, who is appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that all information you give to this committee must be truthful. I also advise that the committee has authorised that for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses have the right to request their evidence be taken in camera and/or remain confidential. Could you advise us now if that is the case?

**Mr BURROW:** No.

**Mr POOLE:** For the Hansard record, could I ask you to please state your full name and the capacity in which you appear today.

**Mr BURROW:** My full name is James Nathaniel Cecil Burrow. I appear as a private individual but I am a practising medical practitioner, a specialist in internal medicine. As such, I have day-to-day dealings with many terminally ill patients. I do work at Royal Darwin Hospital.

**Mr POOLE:** If you would like to start by speaking to your submission, we can then move into question and answer format.

**Mr BURROW:** I will not read it. I came here mainly to answer any questions which you might have rather than to go over ground which has probably been gone over many times before.

Perhaps I will start by giving some of my own background. I was brought up in South America, where medical services are very poor. My parents were missionaries, so I had a strong moralistic background. I am Catholic, so that will probably give you my moral point of view already. However, I am not opposed to euthanasia on religious grounds. Historically, the Catholic Church only sanctioned euthanasia at the time of St Thomas Aquinas. That may be of some interest.

I would like to talk briefly about palliative care and the general medical services in the Territory. This is because I believe that, unless we can reassure the public that our services are equivalent or up to scratch with those in the rest of Australia, the introduction of active euthanasia may leave us without a better alternative.

Specifically with respect to palliative care, I think there are important deficiencies within the Territory on 2 levels: both the specialist services of palliative care and what I would call the ordinary doctor palliative care.

---

Not every person who is dying needs to be looked after by a palliative care team. In fact, I would think that it is only appropriate for a minority. Medical training within Australia, including current training and particularly including the training I received, does not give a great deal of attention to palliative care. Also, what is learned in hospital is not always appropriate. There needs to be an upgrading of the skills of the ordinary health practitioner and in particular doctors, with respect to palliative care.

If I may, I will make some reference to the evidence submitted by the previous witness. It is by and large true that doctors, especially in the past, have been afraid to prescribe adequate pain relief because of the fear of addiction. That is a fact. These misconceptions or wrong attitudes need to be corrected. That can only be done by education.

Another problem which applies both to ordinary doctors and specialist physicians such as myself is the lack of time in which to provide good palliative care. The Northern Territory has the lowest supply of specialist medical practitioners in Australia. This has been recognised by the Commonwealth government and also in our own in-house study.

On average, we are 50% undersupplied. In my own field, the ratio of specialist physicians to population in the Territory is 1:15 000, whereas Australia-wide, it is 1:5000. The pressures of day to day work in such a situation mean that there is insufficient time to provide proper care for the individual who is dying. It is a time-consuming business.

What I am really saying is that not only do the skills of the individual medical practitioner need to be upgraded in palliative care, but the number of such practitioners needs to be increased as well.

As far as specialist services go, we have recently conducted a research project at the Royal Darwin Hospital looking at palliative needs. We have reviewed all our cancer patients for the last 3 years..We found that, on average, about 500 patients are admitted every year. These are not necessarily separate individuals; the same individual can be admitted several times during a year. We estimate that, on any given day, 2 beds are occupied by dying patients. Many facilities are required to look after them in a humane environment.

We know that about 50% of people die at home. So if we were to provide a good palliative care service in the Territory, including a hospice or similar service in the Top End, we would need 4 to 6 beds allocated at any one time.

In addition to that, I think we also need a couple of acute beds in hospital for the specialised procedures of palliative care. These include nerve blocks, local anaesthetic techniques, and a lot of things like that which provide relief for the patient. Not only do we need to provide 2 beds for that but we need the money to upgrade them and that sort of thing.

I do not know if you had a submission from the palliative care people. You may have ...

**Mr POOLE:** We will actually be seeing some people right after ...

---

**Mr BURROW:** Right. I will not go into great detail. However, at present we are under-serviced. There is one nurse for the Top End of the Territory, who is only available during working hours. That is not enough. There is one medical practitioner who has just been appointed on a half time basis.

To have a good palliative care service, you need 24 hour care. You need nursing services and you need more than one practitioner available. That needs to be improved. I cannot tell you exactly what you need but it is certainly a lot more than you have at the moment.

**Mr POOLE:** My understanding is we only have a parttime person in Central Australia too and that is only a nurse.

**Mr BURROW:** In my submission, I spoke about radiotherapy. This is an important aspect of pain relief for a person who is dying. It is not available in the Northern Territory. You have to fly to Adelaide or somewhere. I do not think that it is economically viable to have a radiotherapy service with our population size in the Top End. I think you need about 250 000 people, although I am not absulutely sure about that. You would have to find out from someone who really knew. I believe that Professor Ashby is coming.

**Mr POOLE:** Yes.

**Mr BURROW:** He would know. He is a radiotherapist.

Against that is the fact that the patient has to be translocated to another place. That is not something that people who are in their last few days of life want to do. The Territory has done a number of other things which are not cost efficient. I think you need to think about that. Radiotherapy is a very important part of any palliative care program.

Perhaps I can just talk about something which may seem peripherally related. That is ordinary health care services. You must provide good basic medical surgical care in the Territory. We cannot reassure people that in the case of future pain, euthanasia may not be needed. For example, if I can cure someone today, they may not need euthanasia in the future. Now, I cannot reassure you of that. There are many problems with basic medical services, to which I have already alluded. If you would like an example - would you like one?

**Mr POOLE:** Sure.

**Mr BURROW:** There is a virus called Hepatitis C, which you may have heard of. It which causes liver disease and it is the major cause of liver cancer. There are a number of sufferers in the Top End 100 or 200 people. The federal government has recently allocated $20 000 per patient to treat these people. That is a lot of money. We cannot set up a clinic at the Royal Darwin Hospital because the Territory Department of Health does not have the resources to provide $12 000 for all of them just for the nurse. It is a small cost compared with what the federal government is committing and it is a small cost in terms of the outcome. Perhaps 25% of those people will be cured and will not develop cancer perhaps 10 years down the road.

---

I appreciate that we are under financial pressure but these little things have to be dealt with somehow. Otherwise we will be offering people a way out where they may not necessarily need it. That is probably enough about that.

Perhaps I could just talk about my own personal feelings about euthanasia. I have had a few patients come to me and say,basically: 'Will you kill me?' I have refused because, when it came to the crunch, I do not really think I could do it. I would just think: 'This is wrong'. I cannot provide you with a very strong argument for why I feel like that.

It seems to me that there are two conflicting things. We have to consider the good of the individual patient and I will admit that in some instances the best palliative care in the world will not relieve them of their suffering. One can only improvise with those patients. However, you also have children with severe disabilities who might suffer fits every 5 hours. I used to look at them and wonder how they could be enjoying their life. What a misery! I see people like that every day.

The other thing is that it has to be for the common good. Our society has to protect the preciousness of life. It must be our highest priority. If we allow anything to water that down, we are in trouble. I believe that if you start to attack that philosophy, which is central to our society, we will go down the slippery slope. I cannot prove that but I think it will happen.

I know this is an emotive topic but with respect to termination of pregnancy, it is similar. When it was first introduced, the idea was to protect the mother. My observation over the years that it has been in place is that it is no longer that. It is often just a convenient form of contraception. I say that without being a woman and all the rest of it. I think society has condoned things that it would have previously thought abhorrent. I think the same might happen if we start with active euthanasia for the terminally ill. It might become active euthanasia for the non-terminally ill. I am very worried about that. I think that is all I have to say.

**Mr POOLE:** You would have heard some of the evidence given by the previous witness. Do you think active euthanasia is occurring in the Northern Territory anyway?

**Mr BURROW:** I have never observed it. I think the term 'active euthanasia' means different things to different people. To me it means that someone walks into my office and says: 'I am going to die next year. Give me something that will kill me now'. That is what I think active euthanasia is. I do not think that happens. I mean, I have never seen it happen.

What does happen, and it happens frequently, is that a person with a lethal illness, whose life is a misery from pain or breathlessness or a stroke or something, is not given treatment. That happens all the time.

**Mr POOLE:** Or other treatment is given but the intention is to improve the quality of life even though it might result in death.

---

**Mr BURROW:** The intention is to relieve their suffering but in the full knowledge that they are going to die. I can give you a couple of recent examples.

An old man had suffered a stroke and I said to the relatives: 'There is no point in prolonging this man's life. Let's not feed him or give him a drip or anything. He will starve to death essentially or dehydrate'. That is what happened. He was given morphine. I call that passive euthanasia. Other people might call it active.

A young man had had a brain tumour for a long time. This happened just a couple of weeks ago. He could not eat properly because every time he tried to swallow it went into his lungs, causing him to cough and all the rest of it. His life was a misery. His social circumstances were terrible. I do not think this will identify the patient; I hope not. His wife was about to have their first child a young family. What a terrible situation. I said to the wife: 'I do not think we should put a drip in him because he will not eat. If we do that, there will be endless putting drips in and out. He does not really know what is going on. We could put in a tube to feed him but he pulls it out all the time'. She said: 'No, I do not want that. I would like you to put a drip in him.' I thought: 'Okay, that is fair enough'. This went on for a while and then he got pneumonia one day. I said to her: 'I do not think we should treat this'. She said: 'Yes, you are right'. He died the next day. That is how I think it should be done.

There is no need for a new law for any of that. We do it every day of the week. It is always done in consultation with everyone. I would never do it without full consultation with the relatives and with the nurses, making sure they thought it was all right. I think most medical practitioners now do that.

**Mr POOLE:** What about the ones that do not? I mean, people may be worried about going down the slippery slope, so that voluntary euthanasia becomes involuntary. You obviously are. One would accept that there are people who do not have the same moral ethics or the same reasoning as you. You are obviously concerned about them. Would you not you say the same thing about people who are maybe not doing what you are doing in other words, deciding not to put the drip in without even consulting with relations, family or nurses?

**Mr BURROW:** I cannot answer for their actions. I do not think legislation will change that. Also, I do not think that it that happens very often any more. Attitudes certainly have changed. Where I work, nurses frequently say: 'Why are you doing this? Why are you prolonging their life?' Sometimes I disagree with them and I say: 'I think we should be doing it'. Someone has to make a decision and in our society, it happens to be a medical practitioner. It has been that way for a long time and I do not think that it will change soon.

**Mr POOLE:** Can I put it to you that the situation is quite apparent from public statements that are being made not only here but interstate. A couple of doctors up here have basically said that they have assisted people to die. There are some doctors who do assist people to die. As a citizen of the Northern Territory rather than a legislator, my concern is: are they doing it in the correct way or not? I do not know and I suspect that nobody else knows. Maybe that is an argument in favour of euthanasia, that at least it should be above the table. It is something that this committee will have to address and comment on.

---

**Mr BURROW:** If it is happening under the table, it should be brought out into the open. I agree with that absolutely. However, it is always really hard to know what people are doing when they say that. A visitor from Adelaide told me that he had committed euthanasia in one instance. I asked him how he did it. He said: 'The patient had intolerable breathing problems and I gave him some morphine'. I said: 'How much did you give him?' He had given him 15 milligrams ..It is only a small dose and I would do that anyway. I do not call that active euthanasia. He thought that was a lethal dose but that is his inexperience.

**Mr LIM:** Yes.

**Mr BURROW:** It is very hard to know what people mean when they say they have actually done it unless they spell it out. However, if they are doing it deliberately to people who are wide awake and alert, they should either be punished by law or it should be decriminalised.

**Mr LIM:** The way I see it, there is a difference between what happens in hospitals and in private practice. In hospitals, most actions of practitioners, be they nurse practitioners or medical practitioners, are scrutinised by their colleagues. It is harder to hide what you are doing. If you pull out a tube or put one in, somebody else will notice. The possibility of somebody committing euthanasia in a clandestine way is more likely to occur in a home situation involving a private practitioner. In a hospital, this could not occur because everyone is under scrutiny by everyone else. In a private situation, nobody is looking over your shoulder. That is the big difference.

**Mr POOLE:** That is an area which this committee will have to address when it talks to GPs. If a person has been in hospital with a serious illness and then goes home because no further treatment is available in the hospital, they are dealing with their GP again. The GP then effectively has the long-term control of the patient and and is the one who signs the death certificate.

**Mr BURROW:** It is very difficult ...

**Mr POOLE:** It is a grey area and I am by no means insinuating that it is a common practice in the Northern Territory. I have no idea. However, I think it is an area that this committee will have to look at.

**Mr STIRLING:** There seems to be a widespread belief, if not universal, that a minority of cases maybe just a handful cannot be assisted by even the best standard palliative care. You seem to disagree with that in your paper and I just ...

**Mr BURROW:** I can only draw from my own experience and I have been thinking about it a bit more. I do change my mind on this frequently. I do not think it is easy to make black or white statements on this issue. I think that I have overstated it in my paper.

I think that you can generally abolish pain if you provide various treatments and procedures. However that is at the expense of other things which we hold valuable, such as the ability to think clearly and be with it. Last year, I underwent a major surgical procedure. I was full of morphine for several days. I hated it because I could not think and I was hallucinating. I am not sure which was worse the pain or that. So it is very hard to say how many people are suffering intolerable pain or otherwise. We certainly are not able to make a number of people feel as good as they would like them to feel. I suppose we are doing them a disservice if we let them live. It has to be weighed against the common good which is the maintenance of life which must be sacrosanct. It is not easy.

**Mrs BRAHAM:** In your paper you talk about symptomatic relief and the giving of high doses in the knowledge that such doses may accelerate death. You are saying that the intention is to relieve suffering but you know that the dose will end suffering through the ending of life. Is that not active euthanasia?

**Mr POOLE:** This comes down to the bioethics argument, whether the intention is to relieve pain or whether the intention is to cease life.

**Mrs BRAHAM:** To end pain.

**Mr BURROW:** I accept what you say. However, I think that the medical professional should be seen as a group of people who are doing their best for the patient. They should not be given the chance to slip out of their responsibility of doing their very best to provide for life. If I had something wrong with me, I would be very worried if I went to someone who I did not actually know well or trust, wondering: 'Is he really going to do the very best for me or is he not?' Obviously, euthanasia is an out. You can never measure that; you can never legislate for that.

**Mr POOLE:** However, I have great difficulty with a situation in which the President of the Australian Medical Association can state on television: 'I have helped 2 or 3 people to die but the law should not be changed'. I do not believe that he has that right. It is either a legal right or it is not. Once again, it comes back to ethics. Did he administer something to relieve suffering, leading to death as the end result, or did he deliberately undertake a procedure to kill the patient? If he did the latter, he broke the law.

**Mr LIM:** That statement is ambiguous though. If you turn off the switch on the respirator, the patient might breathe for another 2 days before dying. Did you assist that patient to die or not? Or did you kill the patient? It is so ambiguous.

**Mr POOLE:** The difference is that turning off the respirator is covered by the Natural Death Act and it is legal to do that. I appreciate that the intent might be the same. However, one is legal and one is not.

**Mrs BRAHAM:** I guess it also brings into question the regulation or the scrutiny of doctors' actions. If we do not have any other legislation covering this at present, there is no scrutiny of what is occurring in our hospitals and in practice. Will this bill provide some scrutiny or will we let it go completely unchecked and unknown?

---

**Mr BURROW:** I do not think that it happens a lot.

**Mr POOLE:** It is only a problem if it happens to you.

**Mr BURROW:** Yes. However, I think that the increased scrutiny of medical practitioners has actually been counterproductive in this area. When I was training, if a child was born with Downs Syndrome and had congenital heart disease and another condition involving a blockage of the bowel, we did not do anything. This was the situation until someone was sued for not saving a baby's life. Until then, everyone thought it was sensible, given the life of misery involved. However, the fear of litigation has now tended to reverse that, and I just wonder whether this legislation might actually aggravate the situation so that practitioners will tend not to give patients the treatment that might provide the necessary pain relief but might also lead to death.

**Mr LIM:** So the grey area becomes black and white.

**Mr BURROW:** Yes. I might not give the dose of morphine which I know will probably stop the patient breathing because scrutiny of my actions might lead to legal consequences. It might be more of a problem than it is now.

**Mr LIM:** That comment is quite significant and I do not think that a lot of people understand it. We talk about giving somebody maximum doses of drugs to relieve the pain and suffering and how the balance may be tipped so that they die. However, the thing is that you do not know they will die. They may die as a result of the high dose. It is not that they will die. They may die. If they do not die, you have achieved your purpose of relieving the pain and suffering and they still live. If they die, they do so because the overdose is really 'accidental' in inverted commas. We do not know whether they are going to die or not.

**Mrs BRAHAM**: It is a fine line on how much ...

**Mr LIM:** Yes, how much can the person take? That point needs to be made clearly. It is not that it will kill them. It may.

**Mr BURROW:** Am I allowed to comment on what another witness has said?

**Mr POOLE:** Sure.

**Mr BURROW:** The previous witness said that half of the health dollar goes on keeping people alive when, you know ...

I do not know whether that is a fact but I could believe it. The implication, however, is that the introduction of euthanasia would be economic grounds. That really bothers me. That is what I mean by the slippery slope. I mean, it has been stated explicitly today.

---

If I might speak about the renal dialysis situation, I am involved intimately on a monthly basis in deciding who goes on dialysis and who does not. I would say that, 3 or 4 years ago, I would have let a lot of people die from renal failure without spelling out to them the advantage of dialysis. I admit that that may have been wrong and I may have been taking a position like that of God by not telling them about dialysis or the whole show. However, I thought it was in their interest. The opposite is now the case.

I can give an example. Yesterday I had a man die. He came from an Aboriginal community and he had been on dialysis. Two years ago, he had end stage renal failure. At that time, I said: 'You are going to die unless you go on dialysis. Do you realise that means coming to Darwin for the rest of your life, being on a machine and in and out of hospital? It is a miserable life and, on average, you will only live for 2 years anyway'. He told me that did not want it. But then everyone else got to him and said:

'You know, you really should' and all the rest of it. So he agreed. He has just had the most miserable 2 years.

So opening up to consultation and everything can be counterproductive. I do not believe that we put patients on these things anymore without asking people about it. The evidence for that is the huge numbers of people who go on dialysis. It is phenomenal. We have no spaces left in the Territory for anyone.

**Mr STIRLING:** I do not know whether you can answer this. Perhaps some later witnesses might be able to do so. However, in terms of palliative care needs in the Northern Territory, do you have any ballpark costs?

**Mr BURROW:** Money?

**Mr STIRLING:** Yes. I think you mentioned ...

**Mr BURROW:** You would need a full-time doctor and a couple of nurses. This is for the Top End only and perhaps you ought to double it.

**Mr LIM:** You would need a couple of nurses because you need to cover 3 shifts a day plus holidays, plus ...

**Mr BURROW:** I think they can educate others. At a minimum you would need 3 nurses and one doctor. You would need to provide for specialist doctors to devote some time too.

**Mr STIRLING:** That is a few hundred thousand already.

**Mr BURROW:** You would need 6 beds. That is $500 a day.

**Mr POOLE:** Perhaps $1.5m to $2m to cover the major centres.

**Mr BURROW:** I would not like to put a figure on it.

**Mr POOLE**: I do not want to disclose anything from budget Cabinet. Those are things we have been talking about.

**Mr STIRLING:** It came off the top of the head pretty quickly though

**Mr BURROW:** I don't know. It is a lot of money.

**Mr POOLE:** That is just one area, of course. That is the problem.

**Mrs BRAHAM:** I would just like to ask one final question. You said earlier that 2 beds at Royal Darwin Hospital are dedicated to people who are dying.

**Mr BURROW:** No, they are not dedicated. We know that at any one time, there are 2 such people. They may be in a ward with 4 other people with nowhere for their relatives. It is not very good.

**Mrs BRAHAM:** So how many patients are we talking about in this context in Royal Darwin Hospital?

**Mr BURROW:** People who are terminally ill?

**Mrs BRAHAM:** Yes.

**Mr BURROW:** I suppose everyone ultimately ...

**Mrs BRAHAM:** Everyone is dying anyway.

**Mr BURROW:** At any one time? It is hard to know. I do not have accurate figures but I would say that at a very rough guess ...

**Mrs BRAHAM:** Over a period of a year.

**Mr BURROW:** That is in the Top End ...

**Mr LIM:** You were talking about 500 admissions a year. That is what you were saying.

**Mr BURROW:** To the Royal Darwin Hospital. Not all of those are in palliative care.

**Mr STIRLING:** Sure, I understand that.

**Mr BURROW:** But they are all eventually under palliative care. I think that is about 300 patients.

**Mrs BRAHAM:** Thank you.

**Mr POOLE:** This has been very interesting. Thank you.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 15.35 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative: Palliative Care Nursing, Darwin

Mr Mark Donald, Asst Director, Nursing Management, Darwin Urban

Ms Annie Black & Ms Clare Pullen, palliative care nurses.

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

1

---

**Mr POOLE:** I welcome the following witnesses appearing to give evidence before the Select Committee on Euthanasia: Mr Mark Donald, Assistant Director Nursing, Royal Darwin Hospital; Ms Annie Black and Ms Clare Pullen, palliative care nurses.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise you that the committee has authorised that for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise me now if that is the case?

Thank you. For the Hansard record, could I ask that witnesses speaking to the committee state their names and the capacity in which they appear today.

If you have no objection, you can commence by speaking to your submission, after which we will have a general question and answer session

**Mr DONALD:** Thank you. Firstly, I would like to state that I am Assistant Director of Nursing, Darwin Urban Community Health not Royal Darwin Hospital.

**Mr POOLE:** My apologies. I hope that we have not put anybody's nose out of joint.

**Mr DONALD:** My name is Mark Donald. I am the Assistant Director of Nursing, Darwin Urban. I am responsible for the palliative care team, which is communitybased. My background experience was as a McMillan home care nurse in Northern Ireland, where I set up the first of six home care teams in Belfast.

Annie Black is a palliative care nurse who has worked in Darwin for the last year and a half. Clare Pullen has been with the palliative care team in Darwin for the past five months. Clare also has experience from Sacred Heart Hospice in Sydney.

Today we propose to work through the submission which outlines the palliative care services that are available through Darwin Urban Community Health. We have not, at this point, had any discussions with Royal Darwin Hospital with respect to the development of palliative care services. This submission is from the palliative care nurses.

The philosophy of palliative care is to manage pain and provide physical and psychological support which enables people living with a terminal illness to achieve the best quality of life until their death, and to provide bereavement support to their families. The palliative care nurses and managers do not support euthanasia. It does not fit in with the concept of palliative care.

In our experience, when quality of life is maintained or improved, patients have not requested euthanasia. The patients generally have hope restored and want to live fully utilising the remaining time that they have left.

The palliative care nurses do support the right of terminally ill Territorians to quality palliative care services. There is a need to improve palliative care services throughout the Territory. The establishment of a hospital based palliative care term in Royal Darwin Hospital, a 4 to 6 bed palliative care unit, and an extensive home respite service for carers of those patients who are terminally ill, would be seen as the priority areas of development of palliative care services across the Territory.

I reinforce at this point that this submission does not address the issues of Health staff outside the Darwin urban health district, and is presented only from the community nurses' perspective.

The background information on palliative care services in Darwin is that the Darwin urban palliative care team commenced in 1990. One registered nurse was appointed in Darwin to provide a special resource service for dying patients and their families. The funds for this position were provided from existing resources within Darwin urban health services.

This position worked in isolation from 1990 and was supplemented in March 1994 by a second palliative care nurse. This nurse also provides relief for the respiratory specialist nurse. I will add that this was also met through the existing resources by reallocation.

The Commonwealth palliative care project has enabled the expansion of the palliative care service within Darwin and will allow for some limited consultancy services within the Territory.

The primary carers in the community are the general practitioner and the community care nurses. The aim of the palliative care team is to support and advise those primary carers as well as to support the patient and the family.

What we have given next is a breakdown of statistics concerning clients we have seen from July 1990 until December 1994. The bottom column is only for 6 months. We would expect about 100 patients to be referred to the palliative care team this year. I have also given a breakdown of the total deaths of those patients. This includes deaths at home and deaths in hospital, as well as discharged patients who have perhaps left the Territory or had a diagnosis that was not terminal - in other words, patients who were initially assessed and accepted but later discharged. I have also included Australian Bureau of Statistics figures on deaths from neoplasms or tumours both malignant and benign. Based on those figures, we would probably see about onefifth of the terminally ill patients in the Territory.

Page 4 describes the composition of the palliative care term with a breakdown of sources of funding for the positions. We have a parttime medical officer, who was appointed on 1 March this year from funding from the Commonwealth palliative care program.

**Dr LIM:** That is the $80 000 you got just recently?

**Mr DONALD:** It was $83 000 or $84 000. It is for that position as well as the development of other services within palliative care. Altogether, the Commonwealth palliative care program is an allocation of money over a 4 year period which ends in 1997. We will be building on the palliative care service with that money.

The 2 community nurses are both funded by the Northern Territory government. The psychologist who works with the palliative care team for 4 to 6 hours a week, including 2 hours for meeting with the team and the other time for consultation with families, is based in Casuarina and funded by the Northern Territory government.

The social worker is available through Casuarina Community Care Centre. The pastoral care worker, Reverend Pat Williams, is based in Royal Darwin Hospital. Pat would probably spend about 2 hours a week with the palliative care team. She principally sees inpatients at Royal Darwin Hospital but she is available to do home visits.

The final member of the palliative care term is the Northern Territory AntiCancer support services coordinator who is available up to 25 hours a week for the support of patients with a cancer diagnosis. Palliative care is only a limited aspect of her complete role, which is also funded through the Northern Territory government.

The palliative care resource team provides a community based consultancy service liaising closely with the primary carers the GP and community care nurses - as well as the hospital services and the family. The role of that team is provide specialist advice and support on issues relating to death and dying. This includes: specialistadvanced knowledge and symptom control and pain management; support, education and counselling for the patient and the family; education of health professionals; and followup in the bereavement period for the principal carers.

The principal reasons for referral to the palliative care team are: pain and symptom control; support for the client, the family or other people who may be involved in the care of that person; and specialist assessment and coordination of caring for the family and the patient.

Page 5 shows the average contact time for a client of the palliative care team. In 1990, contact time averaged 48 days. In 1993/94, that has risen to 94 days of average contact time. Some people may be with the team for only 1 day. The maximum length of stay with the team has been 270 days. In other words, there are broad variations in the amount of time a client spends with the team.

The intervention provided to each family by the palliative care team will vary according to the need of that family. Patients are assessed on referral and the plan of carers established between the patient and the family. Initial contact with the palliative care team may be weekly but as death approaches it may become daily, or there may be phone contact 4 or 5 times in the final day of that person's life.

The submission lists the difficulties that the palliative care team has encountered in Darwin. With no radiotherapy facilities, there are sometimes occasions when pain persists because there is no facility to actually reduce the size of the tumour that is causing that pain. The fact that there is no hospice means that there is no alternative way of providing appropriate inpatient palliative care in Darwin.

In Darwin our terminally ill clients our patients have to compete for scarce acute beds. Research shows that terminally ill patients are not demanding patients and that their nurse contact time in hospital wards may only average 10 or 15 minutes in a 24hour period. Contrary to the belief that terminally ill people are demanding, the research shows that this is not the case.

With no dedicated hospital beds, uncontrolled symptoms in the community may get out of hand. If there were dedicated hospital beds, a patient could be brought in for 24 or 48 hours and have their symptoms managed so that they could then be returned to the community.

There is often a lack of continuity when terminally ill patients appear at hospital. Junior staff who are not experienced in palliative care may feel that the doses and the use of the medication are inappropriate and may therefore go back to the standard safe medical levels of drugs.

Another difficulty in Darwin is the limited access to medical personnel. As we have already said, the Commonwealth palliative care program has enabled a parttime medical officer to begin work. That person will have a coordination role to ensure that the patient has continuity of care and that medical practitioners and nurses change their treatment regimes to ensure that there is adequate symptom control. This position is community-based with a role of supporting general practitioners and the patient in the community. It is not meeting the need of Royal Darwin Hospital to look at symptom control. We need to keep him on the community side to ensure that general practitioners have access to symptom control.

Another problem in Darwin is that not all clients have a general practitioner. Many of the general practitioners in Darwin do not provide a home visiting or after hours service. The continuity of care of these patients is disrupted when the patient needs medical attention. They have to go to an acute accident and emergency department.

Another difficulty is that there is no respite for families or for patients in the community. The principal reason for patients dying in hospital is that the family or the carers do not receive respite to enable them to continue to care for the patient in their home environment with the support that is needed in the community. Another issue in relation to respite is that palliative care patients are not eligible for nursing home placement.

The final difficulty that we encounter is that there is limited after hours and oncall nursing service in Darwin. After hours we only have one nurse available in the whole of Darwin urban to cover Palmerston, Casuarina and Darwin.

---

The Commonwealth palliative care program will enable a limited home respite service to be developed. There is presently no service available under which a registered nurse can stay overnight in a patient's home so that that family can at least get 8 hours of sleep knowing that the patient is in good hands.

Another issue is that the oncall service for patients and families is limited to the final stage of dying where the patient is bedridden. That oncall service is provided by general community care centres, from their existing resources. There are no extra staff to cover a situation where, for example, a nurse has been called out at 2am. There are no extra staff to cover that nurse's workload on the following morning. Those are the principal difficulties that are encountered.

The purple-coloured leaflet is the general leaflet issued to all general practitioners and principal agencies who have contact with terminally ill people. The leaflet was issued in December 1994 to promote the palliative care service. Pages 8, 9 and 10 contain more detailed information for the committee on the palliative care service. That completes the submission from the palliative care team.

**Mrs BRAHAM:** You must get scenarios where symptom and pain control is not effective. Some of the patients are in a terminal stage. What do you do then? Do you increase their dose of drugs, morphine or whatever. How do you overcome that?

**Mr DONALD:** Annie might be the best person to answer that.

**Ms BLACK:** My name is Annie Black, and I am a palliative care nurse specialist. In that type of situation, I would go in and personally assess that client's pain. In so doing, I would not only assess physical pain but I would also consider spiritual, psychological and social pain. People often express as physical pain, concerns or problems that are spiritual, psychological or social. It may be that the physical pain has increased. In such cases, we titrate their doses of morphine accordingly. This does not necessarily mean that we can, as people put it, 'bomb them out' if that is done correctly. At that stage, disease has a role to play in how they are mentally as well.

Often it is not necessary to increase the doses of medication if patients tell you that their increasing physical pain is actually an expression of psychological or emotional problems. All it takes is to sit down with them, work out what is happening with them and their family at that particular time, spend some time with them, and perhaps work out some plans and strategies to overcome the problems. In my experience, that has always worked.

**Mrs BRAHAM:** I asked the question because we have received some evidence that euthanasia has been practised by giving excess doses, knowing that they will not only relieve pain but will probably end up in death. I was wondering whether that is the experience you people have.

**Ms BLACK:** No.

---

**Mr DONALD:** In my experience, I have seen persons who have quality of life on doses that are 180 times the normal dose of morphine. That has been worked out and assessed, and the patients have been able to get up and do reasonably good quality things around their own homes, achieving small goals which enhance their quality of life.

**Mr POOLE:** You made the statement at the start of your submission that the palliative care team does not believe in euthanasia in the general sense. It was linked to a statement that it just does not fit in with palliative care. I would suspect that there might be other reasons as well be they moral, ethical, religious or whatever which you might volunteer to me. I just cannot relate to the notion that you do not support it simply because it is incompatible with the idea of palliative care. I presume that there is the odd patient for whom you cannot do anything, no matter how good your team is, and that you cannot relieve their suffering for whatever reason.

**Mr DONALD:** We are the majority of the palliative care team but there other members. We are not speaking on behalf of the palliative care team. We have said that we do not support euthanasia in so far as palliative care is about quality of life and living. It is about making best use of the time that is remaining. As Annie has said, it is about pain control, symptom relief, relationships with family, reconciliation and ...

**Mrs BRAHAM:** But it is also associated with dying.

**Mr DONALD:** It is also associated with dying and dying is a normal part of living. As nurses who have specialised in palliative care, we have worked out where life fits into death and where death fits into life. I think that it is important, in dealing with palliative care clients, to ensure that you as the carer have worked out your philosophy of life and where you fit in.

**Mr POOLE:** I repeat the question. We have heard evidence from other people that there is a very small percentage of people whose pain and suffering you cannot relieve.

**Mr DONALD:** It is documented that about 96% of people will have improved quality of life, so about 4% will have a difficult death. From my experience in a 3 year period in Belfast looking after 350 dying patients and their families, we had extreme difficulty in controlling the pain of about 5 of those patients.

**Mr POOLE:** I am not suggesting that that those 5 patients would have automatically have said: 'Please send me on my way'. I am just interested in the percentages, how many people ...

**Dr LIM:** What would you do with those people?

**Mr DONALD:** It is a challenge to us, as palliative care nurses, to walk beside that person to confront the fact that we have difficulty as well and to show them that we are there to try to support them and take them through.

7

---

**Dr LIM:** Some palliative care professionals would say that euthanasia is another modality in the overall treatment of the terminally ill person, that in fact euthanasia is another stage of treatment. While 96% of patients would achieve a satisfactory dying process with palliative care, the other 4% should get euthanasia as a preferred treatment by the professional, therefore covering 100% of patients. How would you rationalise that?

**Mr POOLE:** It would not fit in with a romantic Irish philosophy - with the greatest of respect.

**Ms BLACK:** Can I suggest that, when people find themselves dying, they often have dramatic changes of attitude. In my experience, they cling to life for hell and leather. They want to live because there are still things they want to do. I am also aware there are medical treatments such as nerve blocks and other processes to which our patients do not have access.

**Dr LIM:** Does the anaesthetic department at the Royal Darwin Hospital not provide you with those sort of services?

**Ms BLACK:** No, not as yet.

**Dr LIM:** I am surprised.

**Mr DONALD:** Because we are nurses, it is often quite difficult to get through the hierarchical structures.

**Dr LIM:** It is happening in Alice Springs and I do not see why it is not happening in Darwin. Alice Springs is a smaller centre. I was part of the general anaesthetic department until last year and we used to do that routinely. Why is it not happening at Royal Darwin Hospital?

**Ms BLACK:** I think that the problem lies in communication amongst junior practitioners, the support we get from them and perhaps lack of knowledge. I am not saying that they are not good general practitioners. I am saying that there is a lack of knowledge about pain and symptom control in palliative care. They are perhaps not aware of ...

**Mr POOLE:** That is the problem, isn't it?

**Ms BLACK:** ... the things that can be done for these clients. As nurses, we cannot just go in and say: 'Do this for that person'. You cannot do that. We discuss things and it is up to them whether or not they take our comments on board.

**Dr LIM:** Is there a pain clinic at the Royal Darwin Hospital?

**Mr DONALD:** There is a visiting pain specialist who comes up.

**Dr LIM:** You have a very large anaesthetic department up here compared to what we have in Alice Springs. Do you have a pain clinic run by the anaesthetists?

---

**Ms BLACK:** I believe there is a pain clinic. Do not quote me on this but I think it might be held once a month. It is for chronic pain.

Often, terminally ill clients are not in a condition to just get in a car and go to hospital, to sit in an uncomfortable chair for as long as it takes for them to be seen, to sit in an office to talk to someone, and to then return home in the car. That is awfully taxing for patients and their families.

**Mrs BRAHAM:** What percentage of patients ask you to end their suffering? Would you know the figure?

**Ms BLACK:** I can remember 2 out of 160. I must say that, when I chatted with them, probing into why they felt that way, they told me why. We sorted those problems out and they never asked me again.

**Dr LIM:** Do you think they just gave up because they did not see any point in asking?

**Ms BLACK:** No, I do not think so. I think they genuinely had something to say but were expressing it as physical pain.

In palliative care, you get down to a lot of tintacks. When death is imminent, you know you only have so much time left. People want to sort things out, perhaps get their life together and get their affairs organised. That is what they want to do. They have made up their minds to do that and to sort out any problems they may have had. Perhaps they have not talked to one of their children for 12 years and they want to reconcile with that daughter or that son.

When they decide they need to come to terms with things that they have not come to terms with in the past, that is what they need to do. Often they will describe a genuine problem to you and are very relieved to have some assistance in solving it before they die. That is what death with dignity and peace is all about.

**Mr POOLE:** So a vast percentage of your time is virtually taken up with psychiatric social issues.

**Ms BLACK:** Palliative care is very holistic. Whilst pain and symptom control is a big issue, if you look at it in a circle, you see that physical pain can be made worse by other problems and that other problems can be made worse by physical pain.

You cannot treat one problem without treating an entirety of problems. If they say they have physical pain, you cannot just say: 'Here, have some more morphine'. They may not be telling you that they actually have an increase in physical pain. They may be telling you: 'I am really worried about my wife. I am worried about how she will cope with my dying and I want to make sure that she is looked after.' That is what they are actually telling you when they say: 'Oh, my pain is getting worse'.

---

It takes some experience and knowledge to probe a little bit further, rather than to assume that what is said straight off to you exactly describes the problem. You really need to probe a bit more.

Often a patient has been referred by a GP or the community nurse. They say: 'The patient has said this and this and I am really unsure what to do about it. Can you look into it?' When I have probed a bit more, I have come out with a completely different story and a happier patient because we have looked at exactly what is going on. They have felt comfortable talking about it and we have helped to start sorting it out.

**Mr STIRLING:** Mark, earlier we heard Mr Burrows talk about palliative care needs in the Territory, to which your submission also makes reference. It states that there is a need for extensive home respite service for carers of patients who are terminally ill. How would that work? What are the implications What does it mean?

**Mr DONALD:** The principal implication would be the ability for a registered nurse to stay with the patient overnight or for several nights, enabling the family to care for the patient during the day. Caring for someone, especially in the terminal phase, is really quite demanding both emotionally and physically. The aim would be to develop that service fully.

**Mr POOLE:** It could also be an initial thing. I know that in the UK people stay with the family for 3 or 4 days initially, to teach the family how best to look after the person.

**Mr DONALD:** Many issues in palliative care are really about fear. These days, people do not come into contact with death and dying as much as they did in years gone by. People can reach 50 years of age without ever having been with a dying person or seeing somebody dead. If you are in a relationship with somebody and you find that person withering away before you, you need a lot of support to understand the normal process of dying and to be able to support that person.

In this respect, Northern Ireland and Australia are completely different culturally. In Ireland, death normally takes place at home. The coffin is in the house and you have tea beside the coffin. Death is very much more a part of living, whereas in Australia we tend to move it out of sight and deny that it is happening. So palliative care is about supporting people through a normal life process.

**Dr LIM:** It speaks volumes for having wakes; that is what happens in the Chinese tradition as well.

**Ms BLACK:** Death is not a medical event; it is a social event. In my experience I have found that people seem to turn death into a medical event. It is not a medical event; it is actually a social event. It is a time when the family is involved in a lot of relationship formation, reconciliation, problem solving or whatever. It is a very social event.

---

When we care for a patient and their family, we walk alongside them and reassure them that they can do a lot more than us because they are the family. They can provide a lot of support for the person who is dying. We can support them in symptom control and so forth but the family is a major part of palliative care as well.

**Mr STIRLING:** Mark, we heard earlier about the strict hierarchical structure that exists in the health world and how difficult it is for nurses to speak out on occasions. I note that you have a medical officer for 20 hours at the moment. If you ended up with a full-time medical officer, surely that would strengthen the negotiating stance of the palliative care team within the hierarchy.

**Mr DONALD:** I think steps to obtain a palliative care medical officer were initiated nearly 2 years ago, when the need was recognised. We initially have the officer for 20 hours a week. I believe that the hospital is envious that we have that resource and sees the need for the development of its palliative services. So if we had a fulltime medical officer to cover both community and hospital, the Top End would be certainly much better off. That does not take into account the situation in Gove, Tennant Creek, Katherine and Alice Springs. That person is meant to have a role in education right throughout the Northern Territory so we are asking him to do an awful lot.

**Dr LIM:** Let me ask about the tables on page 3. Your figures have obviously gone up. You talk about the number of clients being reasonably stable for the last 3 years, then an increase. Is this because of the services you are now providing or are there more terminally ill patients in the Darwin community who require palliative care? Are they coming out of the woodwork because your services are available or are there more patients?

**Ms BLACK:** It is difficult to say exactly why. There could be several reasons. We can only go on the figures provided by the Australian Bureau of Statistics and the client statistics kept by the palliative care nurse. I know that, in my time in the job during the last 18 months, I certainly have tried very hard to improve knowledge of the service and what we can do for patients. I know that referrals have increased.

This year, we are looking at a 33% increase on the 1993-94 numbers. Judging by general comments I have heard, the team is becoming more well known. Health professionals are becoming more aware of it. We are advertising ourselves, as in the pamphlet given to the committee. People are coming to realise what we are able to do and we do a great job considering the resources we have and are starting to use us.

Since the euthanasia debate started, the number of selfreferrals has increased. We used not to get many but we have had numerous selfreferrals over the last few months and referrals from families. We get interstate referrals from Royal Adelaide Hospital. We get referrals from palliative care services. If, for example, someone is dying of a terminal illness in Victoria and is coming up to see their relatives for the last time, we get referrals asking us to keep an eye on them and monitor them while they are here. They are coming from everywhere.

---

**Mrs BRAHAM:** Page 5 refers to contact time. Is there any particular reason why this has increased so greatly?

**Mr DONALD:** I think perhaps it is because people are more aware. Certainly, 10 years ago in Ireland, most referrals were made 24 or 48 hours before the death. I kept going back to the health professionals saying: 'That is not what we are here for.

We are here to try and build a relationship and to support people through the whole dying phase'. So I would suspect that one of the reasons is that education has resulted in a better understanding of the role of the palliative care team in that 3 to 6 months before death.

**Ms BLACK:** I think that general practitioners are realising that, if death is to occur with dignity and peace, preparation is needed for the patient and the family. They are referring patients much sooner now.

**Mr POOLE:** All right. Are there any further questions? Thank you very much.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 16.20 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative: Doctors concerned about euthanasia.

Dr Tarun Weeramanthri

Dr Vicki Beaumont

Mr Alan Bromwich

Dr Ted Giblin

Dr David Ashbridge

Dr Syd Selvanayagam

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

---

**Mr POOLE:** I declare open this hearing of the Select Committee on Euthanasia, and welcome the following witnesses on behalf of Doctors Concerned About Euthanasia: Dr Tarun Weeramanthri, Dr Vicki Beaumont, Mr Allan Bromwich, Dr Ted Giblin, Dr David Ashbridge, and Dr Syd Selvanayagam, who are appearing to give evidence.

This is an intelligence test for politicians, isn't it? Which I just failed.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee should be and must be truthful. I also advise that the committee has authorised that for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply.

Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise me now if that is the case, ie do you wish it to be in camera or do you wish it to be not in camera? Not in camera, okay. If there are specific things that you want to discuss in confidence, as long as you indicate that we can delete it from the written record.

For the Hansard record before you speak, could you please state your full name and the capacity in which you appear today.

What we have done so far is allow people to say whatever they want to say and then we go into general question and answer situation; if you are agreeable. Over to you; thank you for appearing.

**Dr BEAUMONT:** I will start the ball rolling. My name is Dr Vicki Beaumont; I am part of the committee of Doctors Concerned. I am a general practitioner practising in Nightcliff and practising more than 10 years in the Territory.

Names from right to left, as you know, Tarun is a physician and public health researcher. Allan Bromwich is a surgeon; Ted

Giblin is a family doctor. David Ashbridge is a senior rural medical officer and Syd is a physician.

I was going to talk a bit about the history of our group. We have called ourselves a grassroots group, so we are not affiliated officially with the AMA or political or any organisations. We all hold varying views on religion and philosophy etcetera; we have come together over this issue of the proposed legislation on euthanasia specifically.

The group started with 3 doctors the first week in March and we have an ambition of more than 80 and a mailing list of more than 90, and it is growing daily. There are a lot of doctors concerned about this, and we feel that we do speak for our profession even though not all of our profession are members and I think it is probably because of the apathy of the medical profession and any other professions, unfortunately.

2

---

Our main concerns are how this legislation will affect the practise of medicine in the future and also the effect it will have on our community. We have been taken aback at the rapidity of the legislation and we thank you for listening and having the opportunity to speak to you. I hand over to David now.

**Dr ASHBRIDGE:** Have you all got a copy of our submission?

**Mr POOLE:** Yes, we do.

**Dr ASHBRIDGE:** The first point that I would like to highlight is, I believe that the legislation, the issue, has been portrayed in a simple manner and I would like to argue that it is in fact a very complex issue which does not sit easily with the rapid process and I think that the complexity needs to be teased out so people can understand the implications of the legislation.

One aspect of that complexity I would like to talk to now is the notion of the supremacy of the individual or the individual rights issue which seems to be the major tone through the bill. Clearly there is a balance in our society between individual rights and community good and we make those decisions all the time; we have made them in the past in terms of the rights of seatbelt legislation, etcetera, etcetera, and I believe that in this case, that we need to think about what is the common good, whether that is associated with this, and balance that off against what may be the individual rights, and I think that is actually a very complex argument and I would like to take heed of that.

I would be prepared to argue that the common good as in the case of seatbelts or in the case of cyclones is of greatest significance, or a more overriding significance than the individual rights argument, and the effect of an euthanasia bill on the community which I think is not emphasised at all in the bill, is the attitudinal change in the doctor/patient relationship, the possibility of the disadvantaged groups in society not being able to have their options overridden or not taken account of, and I think that there is a real risk of the unknown and when we start talking about the individual rights and not even considering the complex issue of the common good.

Have I expressed that ...

**Mr POOLE:** No, I think we certainly understand what you mean.

**Dr ASHBRIDGE:** I mean, there are attitudes that exist within society regarding attitudes to death, attitudes that the medical profession has based somewhere a trust between the doctor and the patient, and to me that is a cornerstone of good health care, and I can see this as breaking that down, and I think once that is broken down, you are moving into the fear - for me - of the unknown of health service delivery.

Do you want to add something?

3

---

**Dr GIBLIN:** On that point only, that the bill really will result, if it came into being, in an attitudinal change in society; it requires that to happen and it also will irreversibly cause a change in patient expectations of doctors and I think that is what I am most nervous about in relation to this particular point.

**Mr POOLE:** It is a bit awkward I guess because we have such a large group, if we do not ask questions as we sort of go along of the individuals, we will probably forget half the questions by the time we get to the end of the discussion.

I accept your point, but I guess at the end of the day whilst you are a group of doctors that all have a common feeling about this, there are obviously some doctors in the community who do not share your feelings, and proponents of the bill would suggest that it only applies to people who sort of hold up their hand and say, 'Hey, me!' and it involves a very small number of people.

I accept there is the slippery slope argument and all those sorts of things but at the end of the day, what do we do about people in your profession who are currently standing up and saying, 'Well I've done it,' but some say 'I have done it, and there is a need to change the law.' Others are standing up and saying, 'Well I have done it,' even your own president of the AMA has stated that, and do not seem to recognise that there is a need to change the law.

**Dr WEERAMANTHRI:** Tarun Weeramanthri. There are a couple of points in there; maybe I could address them in order. The first point you made was about okay, where one group of doctors - as you say, there would be a number of doctors who would be prepared to do this and you quite rightly ask the question, but if we say we do not do it, we will not do it, which we have got a right to say, how is our practise changed? I mean, we discussed this amongst ourselves and it is to do with that question about expectations, and this is difficult to get across.

Currently, if the patient comes to see you, and they have got a serious illness, what you try and do is, you try and talk to them about their concerns and their worries and their expectations, and there are all sorts of ways you do that; you say, 'How are you going? How is the family?' And suddenly we realise that those kinds of questions become loaded in the context of this legislation being present. We do not actually have to agree or practise - agree with the bill or even practise it - for the most innocent question which we ask now such as, 'How is the family going?' to become loaded.

There is a change in the subtle relationship between doctor and patient even if we ourselves do not agree with this and do not practise; probably someone else can pick this up.

**Mr POOLE:** Can I ask you then to develop that argument, wouldn't the same thing apply to the changes that have only occurred in the past few years with regards to terminations? I mean, the same thing would apply, wouldn't it, whereby somebody would come to your office and sit down and talk to you and if they happened to be in the early stages of pregnancy and you say, 'How are you going?' they think, 'Oh, what does he want to do to me,' or, 'What does she want to do to me?' sort of thing.

---

**Dr BEAUMONT:** It is a bit different. With termination and say if the doctor does not agree to refer for termination, they will just walk down the road and get someone else basically and that is available; they can go to hospital casualty and be referred for a termination.

We are more or less talking about our relationship with a dying patient. There is a high proportion of people in a dying state who are depressed, and in order to evaluate the amount of depression that there is there and if they need medication etcetera, and so the questions are, 'Do you ever think of dying? Have you ever thought of killing yourself?'

Now, they are really the loaded questions.

**Dr GIBLIN:** We cannot say that any more, because we are then suggesting euthanasia, unwittingly, to them -not intentionally but suddenly, 'I suppose you have been feeling depressed,' is a loaded statement. Suddenly, 'Have you ever thought of killing yourself? Have you ever felt suicidal?' any of those questions, become loaded. It becomes a difficulty. We have got to avoid talking about death.

**Mr POOLE:** Like I said, I think that is a fairly simplistic statement, but anyway, yes.

**Mr BROMWICH:** It is a question of trust.

**Dr LIM:** I just wonder, I am not sure, I cannot speak on behalf of the other members of the committee but really when you use the words, 'loaded question,' I understand from my medical knowledge what you mean; I wonder whether ...

**Mr BROMWICH:** The point I think we are trying to make here is that a patient who does not know, at the beginning of the relationship with his doctor, whether his symptoms indicate serious illness or not, will if this comes into legislation, will be quite shocked, regardless - because when you first see a patient you say, 'Before we go any further, I should tell you that I am in favour,' or, 'I am against' or that 'I will or will not kill patients,' you do not say that. So the patient does not know.

One of the things that is going to be at the back of their mind is, 'If this is something serious, is he going to start putting subtle pressures on to have me killed? Perhaps I had better not tell him about this symptom in case.' This is a very real thing; this is the way patients' minds work and this destroys this rather precious doctor and patient relationship which is important for the patient because complete honesty is the only way you will get accurate diagnosis and therefore adequate treatment. That is what it is all about. It is the best treatment is the end of the road, and this bill to my mind would put an impediment in the way of that.

**Mr POOLE:** I also mention to you that we have probably a fair mix of views with regard the bill; I mean, we are grassroots people, too, and this is what we are doing, of course, trying to make sure that everybody is in a position to at least debate and discuss the bill knowing the pros and cons for it and there are some pretty diverse views across this table.

5

---

**Dr SELVANAYAGAM:** Can I take it a little bit further. My practise involves treating quite a lot of cancer patients; it is a process that is a continuous process; it might start off with the optimism I am sure but quite often it might end up with terminal illness that will progress and lead to death eventually.

It is a very complex and sometimes very difficult situation to deal with and it involves building trust, building a rapport, and being able to discuss lots of issues and as part of that process you obviously also help that person go through the process of dying which is going through a denial/anger as well as to acceptance.

I must say personally, I cannot speak for anybody else but myself personally, I find it very difficult sometimes to differentiate between somebody who is reacting to a situation that they have learned about as opposed to somebody who has gone through the process and come to realise that this is what they want.

I agree that most patients probably would not want to elect to have it but I think the processes of actually going through and making that decision about who is in fact of sound mind and is able to make that decision, a lot of people will say, 'I do not want to be a burden on my family.' Now, is that something that that person is doing because they think they have pressure from their family to make that decision?

Your duty is to that person, not to the family even though the family is a very vital cog, a very important part of that person. That is a difficult issue for me. The other thing that I also find very difficult is that I think in the current - I saw the palliative team here before and I work with them quite often and intimately - situation is not optional at the moment and I am sure they would have told you about that. I also find it difficult to be able to offer other alternatives which are excellent and not be able to do that in the current situation because I know at the moment for example patients quite often die at home - where they have to die in hospital there is no hospice and so on and so forth.

That is another difficult issue; if somebody says, 'I would rather elect to die' because they know that the other option is staying in a hospital, is that a fair situation to put them in?

**Dr ASHBRIDGE:** One of the things the bill talks about is patient initiated, and I think one of the themes that have been developed along here is that the dynamic of the doctor/patient relationship actually makes that very difficult in the sense that the questions that you could be asked could well be seen to be prompting or even leading someone down that path.

At the end of the day, that may not be the intention, but how you actually come to who made that decision - did the patient make the decision or were they sort of seduced into that decision by the questions that they were asked, would make this bill very difficult to ensure that the decision did arise and was initiated by the patient rather than as the process of a discussion between the two.

6

---

There is no way that you can have cameras and listen in to doctor/patient discussions; I mean, they are there in private and the outcome of them is very hard to tease out as to what the process was, and I would feel very confident that you could not at all guarantee that it was the patient's request.

I think that is an important principle, the one of the dynamic of the relationship.

**Mr POOLE:** The bill as it stands now sort of has the provision that obligates the first medical practitioner to discuss the situation with the second who must also discuss it with the patient. I guess you could never get in human relationships, a completely foolproof system, but I would suggest to you that we do not really have a foolproof system now whereby some doctors are making the decisions for patients without even telling them - apparently.

**Dr ASHBRIDGE:** I certainly would not support that, either.

**Mr POOLE:** No, I am not suggesting that any of you here support that situation and I must also say that we do not really have any evidence of that as occurring in the Northern Territory, but we have been told that euthanasia is happening here.

**Mr BROMWICH:** We are not sure about this, incidentally. We are not too sure about this because at least one of the 7 doctors has referred to increasing doses of morphine which is of course already much ...

**Mr POOLE:** I was about to lead into the debate; we have also been told of course that half the people who are standing up and saying, 'Well, I have done it,' actually according to the letter of the law have not done it. All they have done is that sort of thing, whereby there has been no intent to kill the patient; it has been to alleviate suffering and the death has been a side effect.

**DR GIBLIN:** Absolutely; there is a fairly important distinction in that.

**Dr WEERAMANTHRI:** I just wanted to make that point, Mr Chairman, that Brendan Nelson in fact was saying precisely that, and we are actually trying to say in our submission the same thing, that we as practising doctors have done exactly that, and do not call that euthanasia and do not see that that is covered in this bill.

**Mrs BRAHAM:** But aren't you really kidding yourself a little bit if you are saying, 'We are administering extra doses,' knowing, really, that it may kill the patient.

**Dr GIBLIN:** Absolutely not.

**Mr BROMWICH:** That is not - it is intention that matters.

**Dr GIBLIN:** I think the answer to that question is no, we are not, because the question is intent; the question is a very important distinction. I mean I know that it is a difficulty, but intent is overwhelming.

7

---

**Mr POOLE:** That is of course really a debatable subject on its own; the bioethesis that argue either in support or against the bill ...

**Dr GIBLIN:** I have got some patients in my practise who have signed advance directives which they are sent by the New South Wales Euthanasia Society and what that says is, 'I do not want to be resuscitated or put on machines.' That is passive euthanasia. Other people, I was going to say before, all my patients die at home; they do not all die at home but the ones who do die, almost invariably die at home.

It is an important point because much of the debate that I have observed has centred around dying in hospitals and it is irrelevant to me and to most of my family doctor colleagues.

**Mr POOLE:** Yes, I think we recognise though that just from the evidence that has been given to us, even the people who are attending hospital at the end of a terminal situation usually at the end of this stage, go back home under the care of their GP.

**Dr GIBLIN:** One hopes so, or one hopes that they do not have to go into hospital at all, but of those who die at home there must have been some who died as a result of analgesia, but not with the intent to kill them. They did not go and say, 'Right, it is your time,' or 'Yes, I agree, you have been saying it for 2 weeks and now I am going to do it,' and get out the big needle.

What we do in the community is, if someone has got a terminal illness, that means that the statistics say that they are going to die from it, then we provide adequate pain relief and what we are looking for is the window between adequate pain relief and unconsciousness, and it is a joy to find that sometimes we can give them that much pain relief and they are alive and conscious and they can work their word processor and they are having a good life. They know - they are processing they are dying - because they are conscious and free of pain.

That window becomes smaller and smaller as the illness gets more and more advanced, but what we are always looking for is to provide adequate analgesia and not render them unconscious. Eventually that happens, sometimes. Sometimes it happens quite suddenly. People, as you well know, sometimes decide when their son comes to visit them and says, 'I love you, dad,' and they say 'That is all I really wanted,' and the next morning, they are dead.

So it does not require this prolonged 2 years of unconsciousness, vegetable, to die; they often die by choice.

**Mr POOLE:** I think one of the facts, and there is nothing to back it up apart from percentage things taken out of the Dutch reports and stuff like that, that we have been offered in evidence is that you are actually talking about 12 or 14 people a year under the terms of qualification for ...

**Dr GIBLIN:** Marshall said 18 at a ...

**Mr POOLE:** It depends how you work the percentage, but say it is between 12 and 20, so it is quite a small group of people anyway.

**Mr BROMWICH:** The numbers are not important.

**Mr POOLE:** No, I guess not, unless you happen to be one of the numbers.

**Dr GIBLIN:** Or one of the doctors.

**Dr ASHBRIDGE:** I think that is going back to the idea that it does not have a flowon effect to the attitude in society; I mean yes, you can say, 12, 18, 20, that is not a lot. It will not impact. Yes, you can find doctors who might be interested in doing it, but that is just sort of going back to the complexity of the argument and ignoring the fact that that will colour the practise of medicine.

It is not - and I rate this very strongly - just 12 or 15 people, that it does introduce a change across the whole of the Territory in the way that services are delivered. It is not just 12 or 15 or 20; I think it is a very much more widespread phenomena than that and I think it will infiltrate everyone's practise whether they believe or do not believe in euthanasia.

**Dr WEERAMANTHRI:** Could I come back to your point, in which you asked about the intent - Allan actually ...

**Mr BROMWICH:** I frequently have operated on patients knowing that there was a very good chance indeed of them not surviving an operation. Clearly if there was no chance, you would not operate, but it can be very high indeed and it has been a considered risk.

That does not mean that I even partially intended to kill them, in the same way that when you drive a car you do not intend to knock anyone down, but it happens. No, the intent is terribly important, and is a very, very real distinction indeed, and it effects attitudes which is what we will say.

**Mr STIRLING:** It was put to the committee earlier today that if the bill becomes law, that you could speculate that there could be a greater scrutiny on what goes on in hospitals and doctors' actions with both the terminally ill and patients who have died, and that however common that practise is at the moment of increasing dosages to alleviate pain, that doctors who did not have the piece of paper from the patient requesting to die may very well be loathe to undertake those sorts of practices that they have done quite commonly in the past for fear of being picked up.

**Mrs BRAHAM:** I doubt that.

**Mr BROMWICH:** I cannot see that.

**Mr STIRLING:** You have not come across that?

**Dr GIBLIN:** I think what happens in practise is that we hope that the family doctor has formed a relationship over some years and that that is discussed. I mean certainly I would discuss that with a person who had - I have got 2 people at the moment with cancer who are dying - one presumes we discussed that at some length, what sort of analgesia is the more appropriate, how much is appropriate, and what happens if this gets worse, and they mostly say, 'Look I do not care as long as I do not have the pain,' so we are looking for our window.

We are looking for enough pain relief, but not too much, that is a fine line, we juggle it every day.

**Mr POOLE:** I think the point that Sid was making was that it was put to us by a doctor who does not support euthanasia that the bill itself would cloud him in those sort of issues because he has not got a bit of paper from the person, that is signed, that he will not take the risk of giving that little bit of extra morphine or whatever it is which might have the side effect of the person dying, because he would be worried about the consequence down the road, that here we have a guy who is dying under morphine treatment ...

**Dr GIBLIN:** Fair comment; I have not considered that.

**Mr POOLE:** ... but has not got a piece of paper so maybe he has done something wrong, or she has done something wrong.

**Mr BROMWICH:** That is not the way you think.

**Mr POOLE:** No, it was just put to us by a doctor.

**Dr ASHBRIDGE:** I guess I would like to think we are all in agreeance - we have not got a sort of scripted argument to come with, but in my experience at least, the discussions about levels of pain relief and increase in dosages are not done unilaterally.

If I was to be talking to the patient, you would ask how much pain they are in, should we be increasing the dose, and so the inference from that question is that it was done without the consent of the patient and I personally would not approve of that, and ...

**Mr STIRLING:** There was no inference of that intended. What goes on now, that was put to us, may not go on following if this bill was to become law for fear that there was greater scrutiny and making sure that ...

**Dr BEAUMONT:** Yes, but that is standard palliative care, you see, and palliative care is becoming more and more talked about and performed better in the Territory although we do not have palliative - but you know, that is standard palliative care and I do not think that would suffer myself.

**Dr SELVANAYAGAM:** The only concern I would have is if there is a legal reason why that sort of practise would not be possible; like would this bill take away the Natural Death Act which is currently in place?

---

**Mr POOLE:** No, it does not.

**Dr SELVANAYAGAM:** Right, so I mean from an ethical and my ...

**Mr BROMWICH:** Is there a possibility of the courts finding that it supersedes it?

**Mr POOLE:** No. An Act is an Act.

**Dr LIM:** Let me just address this issue from a different tack altogether. Assuming that this bill gets through, what in it would you like to change or amend to safeguard your patients?

**Dr GIBLIN:** I am happy with the Natural Death Act.

**Dr LIM:** But the bill is going to go through; the numbers are there to get it through - is there anything in there that you would like to change so that it is less onerous on you?

If it is going to go through, what would you do?

**Mr POOLE:** And do not accept from that that the committee is saying that it is going to go through.

**Dr GIBLIN:** I think I would be a nonparticipant, that is all; it would just mean that I would not be a participant. Somebody said to me about 2 weeks ago, 'What is your position on euthanasia?' And I said, 'Well I am not going to be participating in it if it becomes law,' and she said, 'Well what am I doing coming to you then? I might need you at the end.' And she was half joking, but I thought, 'Oh god, here we go.'

Because one of the things that Mr Perron has said repeatedly is that there is no pressure on people; when I mentioned this talk that he gave and as a right of reply to Dr Wake, at a Rotary meeting, he said that if what it took to get the bill through was to have a register of doctors willing to participate, then that would be considered as an option. And I said, 'Well I will not be registered.' And he said, 'That is your right, you do not have to,' but apart from the question of what happens to rural doctors or what happens to one and twodoctor communities - very big problem.

Or even me. I am in Stuart Park in the middle of town and my watershed probably goes from Arnhemland to Tennant Creek - well, I am not making a big deal of it, but I mean people have sort of said, 'Well, which way are you?' So they want to ...

**Mr POOLE:** Let me ask this. Have you ever had any patients ask you to assist them with ...

**Dr GIBLIN:** Yes.

**Mr POOLE:** On how many occasions?

---

**Dr GIBLIN:** I have been here 21 years - plenty.

**Mr POOLE:** Under the terms of the bill as it is currently written, would many of those qualify?

**Dr GIBLIN:** Would they qualify? Yes, I think some of them would; I have got no idea of the numbers now that I think of it, but what I would say is that none of them ended up being euthanased, and I like to think that because I was willing to spend time and make my attempt to increase their quality of life, it showed them that I cared that they probably changed their mind.

That was one of the things that drew me to this group originally, the idea that death is educative and that two groups of people benefit from the dying; one is the dying person - I mean, this is an unpopular view, but it is nonetheless something that needs to be said, I think - that the dying person, sometimes it is the first time that their kids come back and tell them things, that they actually come and listen, that their brother comes from Connecticut to say, 'Listen, sorry about that, that I did to you 30 years ago.'

They learn. They grow, I think, as they are dying, and secondly of course, the family benefits a great deal from that dying process - it sounds selfish, but I think it is a really important ...

**Mr POOLE:** A part of life is death - that is for sure, but you said though that despite the number of people who asked you, none of them were euthanased, and you would like to think that after talking to them about it, etcetera, they changed their mind.

Don't you think that it would be exactly the same even if there was a law that allowed you to do it?

**Dr GIBLIN:** In that respect, yes; I cannot see any difference. I do not think there would be any difference to me, of course.

**Mr POOLE:** I think we all hold the basic principle that life is sacrosanct and what I think now is, I would want to live as long as I could.

**Dr GIBLIN:** I think what David is saying is ....... because it would not make any difference to me personally in my practise because I will continue to do what I believe to be right and best, but it does have this implication on society as a whole, and patient expectation of us as doctors - doctors' expectations of doctors, doctors' perception of medical practise, they are the things that I think - you know, I started to think that this was the beginning of the end of medical practise as we know it, because of that.

**Dr WEERAMANTHRI:** Possibly a good example of that, and we are not experts in this, but David, you might like to talk about the situation with regards to Aboriginal people.

---

**Dr ASHBRIDGE:** This is obviously a very heated topic of debate within non-Aboriginal society and I am pleased that Maurice is here, but there is the issue of communicating the complexity of this debate from one culture to another is in fact very difficult - very, very difficult.

There is a history of - and I will use my words cautiously - distrust of admission to hospital, of not being in control of your own life when you leave your - and to then enter a 7storey building when you are only partially informed or unsure of what the debate is, I can tell you even now there are concerns like, 'Will I leave?'

There is an introduction, even at this stage of the debate, even prior to it being an Act or not being an Act, there is a lack of understanding about what might happen if I go in? Now, I accept that is not the intention of the bill and noone would approve of that, but it is reality.

There is a real concern that an institution - I am talking about hospitals here primarily, but as an extension of the doctor/patient relationship, that there is for me a real concern that the years and years and years it has taken to bring trust into many people coming to hospital and to receiving care in hospital, could be eroded by being very worried that they might not leave.

The process that is being decided on to debate the pros and cons of this debate by and large by the nature and speed and complexity of the issues involved, in fact I think excludes onequarter of the population. I feel quite passionately that as we talk about the bill for the whole of the state, how can we go ahead at this pace, let alone whether it is the right or wrong thing to do, when we are abrogating responsibility?

It is not an inclusive argument, and yet the population we are talking about here, and I find it hard not to talk in sort of resource allocation and that when we have fellow Territorians dying 20plus years younger to talk about introducing comfortable palliative care at the age of 53 or 50, or whatever. It just does not sit comfortably with me, the idea of the lack of communication and the fact that we have got incredibly bad health statistics for Aboriginal people.

One of the perceptions will be, well, one of the solutions is that at least it will be a smooth exit. There is something which does not sit with me very comfortably at all.

**Mr POOLE:** I think you are drawing a long bow, but you are certainly entitled to that, and I guess ...

**Dr GIBLIN:** One of the things that David brought up a few days ago was, what about the basic health facilities before we provide euthanasia for Aborigines?

**Mr POOLE:** I would say to you, a byproduct of this committee has got to be I guess the introduction or certainly the revisisting of palliative care facilities on - probably the one positive thing.

13

---

**Dr ASHBRIDGE:** I think if you use the palliative care argument which I think is fully reasonable, I mean, I think you should pay attention to that, then the extension of the palliative care argument in Aboriginal communities is health services.

I mean, it is exactly the same argument, it is just that if people who do not have access to health services are dying of preventable diseases through lack of health services, then surely before we start talking about palliative care services in that environment, the extension of it is that we should have services capable of getting people to live long enough to enter the palliative care arena, and it is ...

**Mr POOLE:** We are going off into a different area.

**Dr ASHBRIDGE:** We are, but ...

**Mr POOLE:** And I assure you that the committee would accept your point; it is a very valid point but I think we could probably talk about that for hours rather than the bill.

**Dr ASHBRIDGE:** That is fair enough, yes.

**Dr GIBLIN:** The first paragraph on the second page of our submission.

**Mrs BRAHAM:** On a different point again; we have touched on the Natural Death Act a number of times today, but the evidence that was given to us at another time was that the Natural Death Act in actual fact is not very well known throughout the Territory, and that many doctors do not even discuss the options with patients, and in actual fact, it should be promoted more and people should know what options they have.

Would you like to comment on that.

**Dr GIBLIN:** I agree.

**Mrs BRAHAM:** Is it your understanding up here that it is not promoted enough and that it needs a higher profile? That it is really up to doctors then to promote it and to let people know what their options are under that Act as well?

**Dr GIBLIN:** Yes, I think so.

**Mr BROMWICH:** Yes, where relevant. I mean, we are not going to start off a consultation on a new condition regardless.

**Dr WEERAMANTHRI:** The Natural Death Act, you are quite right, is not very well known, but what it really does is it codifies good medical practise which we would all be doing anyway, and it does not actually - when I have read the Natural Death Act I was suitably impressed by it, I suppose because it codified standard good medical and ethical practise, and it is a fact that we do not read it or are very well informed about it which I completely agree does not actually mean that we are not doing those things with patients, because for the most part, I think we are.

14

---

**Mr POOLE:** Yes. Some would argue of course that the same thing applies for the Euthanasia Act.

**Mr BROMWICH:** I think there is a difference between looking after the patients and killing them.

**Mr POOLE:** Yes. So do we, I am quite sure. I think something that maybe people fail to recognise - I do not think any member of Parliament in the Northern Territory thinks that there are a bunch of doctors running around with hypodermics in their hands just waiting to get customers.

It is seen I think by the proponents of the bill anyway, as being a way of alleviating people's suffering. Now, whether or not you accept that, that is what we are debating, I guess.

**Dr GIBLIN:** I believe we can do that without terminating.

**Mr BROMWICH:** Another point on the bill; it discusses the individual who is eligible for this treatment. A doctor has to be of the opinion that he will probably die within 12 months. Incidentally it is not that he certainly will or overwhelmingly will - it is just likely, which means 50%, on the balance of probabilities that the lawyers are so fond of, which suggests to me first of all that a number of people who would not in fact die in 12 months are in fact eligible.

But, more to the point, is the nature of the disease; ............ is not a static thing, it is changing all the time. When I first started medical practise and that is very nearly 50 years ago, tuberculosis was a disease of which a very large proportion of the sufferers one would say were they were likely to die within 12 months. I can still remember there were wards full of young people dying. They do not die now.

In those days leukaemia was invariably fatal. Childhood leukaemia is mostly nonfatal now, and so it goes on, and the mortality from cardiac failure has dropped remarkably in the last 10 years. I have no personal knowledge of this, I understand so from my physician colleagues, and in the circumstances, it is almost arrogant suggesting that the present situation about fatal disease is going to stay that way. It does not.

**Mr POOLE:** The committee actually has already flagged the question of the - for want of a better word - time limit of the 12 months. I think all of us have some queries about that and I guess we have also flagged the definition of, what is a terminal illness today, might be very different tomorrow, for whatever ...

**Mr BROMWICH:** I am glad the point has been raised, particularly since 3 of the 7 doctors in Victoria who say they are killing patients are dealing with a disease which though at the moment is not curable, it may well not remain so - we are talking about HIV infection. I think that makes my point.

15

---

**Dr GIBLIN:** I think the estimate of time left to live has other disadvantages too, and that is that they occasionally become selffulfilling so that people ask, 'How long have I got to go?' Then I say that I am not willing to give an estimate so that if perhaps they have got an 8 out of 10 chance of dying with this illness, I am going to assume that they are one of the two, and that they are not going to die, and that way they are more likely to have a positive experience in whatever time they have got left if they do die, and it may be that they do not.

The other night the only time we have met together, somebody said, 'Well somebody was told that they had 3 months left to live and they lived 4 months and they came back to the doctor and said, "See I lived for 4 months" and then they died soon after. And I said, 'You know why he didn't live for 12 months?' And the reason is, he was told 3 months before.

**Mr BROMWICH:** In actual fact I remember in my career said about a patient, 'You,' or he to the relatives, or he or she, 'has so long to live.' He said, 'If journalists can do this,' - the point being that the prognosis is the most difficult part of medicine. It has been said that no doctor has ever lived long enough to write a book on prognosis, and so this 12 months is demanding from a doctor an ability to foretell the future that no competent doctor would claim.

**Mr POOLE:** I think that I should also note that we have already flagged the idea, I guess, in essence of signing a release form or whatever you call it, the certificate, and then sort of having put it into effect, 'When are you going to do this? Two months later, or 3 months later or tomorrow, or whatever?' That is a big query that we have not sort of - for the same reasons, because of the prognosis.

**Mr BROMWICH:** Again, that is almost a death row thing, isn't it?

**Dr BEAUMONT:** Have you queried the definition of whether the patient is in pain, distress? There were 3 words.

**Mr POOLE:** Yes. We actually flagged that particular clause - conditions under which a medical practitioner may assist, and (d) says: 'The illness is causing the patient severe pain or suffering or distress,' and we basically sort of said that probably it should read, 'The illness is causing the patient severe pain, suffering.'

**Mrs BRAHAM:** Because the distress may not be terminal.

**Mr BROMWICH:** It is 3 'ors.'

**Mr POOLE:** Yes, what is 'distress?'

**Mr BROMWICH:** Your depressed patient is distressed.

**Mr POOLE:** Most are, when we are told we are going to die, I guess.

**Mr BROMWICH:** It would be unreasonable not to be, unless you are already suicidal. Well, think that one through.

**Mr POOLE:** I guess one could almost say that you would doubt whether people are competent of making a decision if they are asking you to put them to death.

**Mr BROMWICH:** Yes, exactly.

**Mr POOLE:** That depends I guess on the moral and ethical standards you have.

**Mr BROMWICH:** This question of competence to decide is very much glossed over in the bill; it is in no way defined and I must say I am afraid it leaves a door wide open which should not be left open.

**Mrs BRAHAM:** But you have the safeguard of having two doctors.

**Mr BROMWICH:** In theory, yes; incidentally there is nothing that says those two doctors cannot be even married to each other.

**Ms ?:** In collusion.

**Dr WEERAMANTHRI:** What collusion? They are just two doctors who are known to favour that, and you can go to the same two doctors every time for every person in the Territory under the bill.

**Mr BROMWICH:** In the old days, before a patient could be cremated, a certificate had to be signed by two doctors. One was the doctor who signed the normal death certificate and the other, the doctor who was ......... seniority in the profession, not related to, etcetera, or in practise with the other doctor - the whole spectrum, clear conditions that they were completely and not only independent, but seen to be independent. There is no such provision here.

**Mr POOLE:** No, but I guess from the same point of view, you now have a situation that you can have somebody who is in a terminal situation whether it has been almost in a palliative care situation being looked after by the family doctor, can die because of the effects of morphine, the death certificate is signed by the doctor who administered the injection and end of story.

**Mr BROMWICH:** Yes.

**Mr POOLE:** It depends which way you want to look at it, whether you are looking at it from - I guess there is no problem as long as all doctors can assure all patients that the intent of the injection was to relieve their suffering.

**Dr WEERAMANTHRI:** Or just an increased oral dose and then doctors can ...

**Mr POOLE:** Whatever.

**Dr WEERAMANTHRI:** I mean, that is current standard practise which has been there for centuries. What we are talking about here is something different, and the degree of certainty this society has to have about the competence and integrity of the doctors has to be a degree higher than what is currently practised.

**Mr POOLE:** Yes. I do not argue with that point at all. The difficultly as I see it is, that you have some doctors who are standing up saying, 'We have committed euthanasia, sometimes involuntary euthanasia.' I mean, it really makes me feel like saying, 'Well, I think everybody needs two signatures on a death certificate.'

**Dr WEERAMANTHRI:** It seems a strange reason to legislate.

**Dr LIM:** Professor Matthews in the back wanted to say something in addition to that if you would let him.

**Mr POOLE:** No, we are in a ...

**Mr BROMWICH:** Obviously our profession has exactly the same proportion of rogues as any other profession.

**Dr GIBLIN:** Cross that out!

**Mr BROMWICH:** Less perhaps than some.

**Mr POOLE:** Lawyers I would suggest............

**Mr BROMWICH:** We will not discuss which, and indeed some of our more notorious murderers have been medical practitioners. That does not mean that the average doctor is not a decent citizen as indeed most citizens are, and neither more nor less, and the same safeguards which are naturally adequate otherwise no murders would occur, have to apply to doctors as to everybody else.

These gentlemen down south who have said they have killed patients to my mind, the next step is the appropriate investigation by the police, as you would for anybody who goes into a police station and says, 'I have just killed somebody.' Investigate it.

But you do not accept it as necessarily being true.

**Mr POOLE:** No.

**Dr BEAUMONT:** The other problem is that in our training we are not trained in ethics and when a patient comes to us asking for us to terminate their lives, there is no way we can judge what has influenced that patient, are there family influences that are not really acceptable in this bill? And that is the other big problem.

Even if you get a second person, doctors are mainly overworked; the population has still not got even enough general practitioners ...

**Mr POOLE:** Wouldn't you in defence of doctors say that normally the average doctor is going to be there saying, 'Look Fred, or Mary, this is crazy; you are nowhere near that stage in your life that you need to sort of hasten it' unless you thought that the person was in really terrible uncontrollable pain and suffering?

**Dr BEAUMONT:** I do not know what is going to happen with that?

**Mr POOLE:** I am just putting the hypothetical question because that is, I am quite sure, the intention of the bill - the intention of the bill is not to accommodate people who are depressed. The intention of the bill is to accommodate people who are in an intolerable pain situation that cannot be alleviated by available medical treatment.

**Dr GIBLIN:** I do not believe there is such a situation. That is basically my view.

**Mr BROMWICH:** And I have yet to meet it.

**Mr POOLE:** That is, I think, a very valid point.

**Dr LIM:** I put a case to a medical person today. You have got a patient with laryngeal carcinoma obstructing, dying of hypoxia, which is a very, very cruel way to die; it will take several days, at best.

Nothing much more you can do, and the person is dying, is struggling to breathe. We couldn't tract them, and the carcinoma has spread below the trachea. What are you going to do with this person, because this person will die within 3 or 4 days. He is going to struggle through, semicomatose, because of the hypoxia. How are you going to deal with that?

**Dr GIBLIN:** It is a terrible scenario. In that situation, you see, I do not have that because they would not be at home in that situation, but in that situation adequate analgesia is my answer to that. That is what I was saying before. I do not believe there is a situation in which I am powerless to do anything - I would provide adequate analgesic.

**Dr LIM:** But the patient is already semicomatose, and not in pain any more, does not appreciate the pain because he is semiunconscious.

**Mr BROMWICH:** Who is distressed? The patient, or the onlookers?

**Dr LIM:** I cannot answer that.

**Mr BROMWICH:** The patient is semicomatose, and not in pain; individual examples are, but in this particular case one wonders whether the distressed people are the people looking after him.

**Dr LIM:** Yes, more than likely, but it is still an undignified death.

---

**Dr WEERAMANTHRI:** Whose dignity are we talking about?

**Mr POOLE:** It is a hypothetical situation; if they are comatose they are not in a position to be saying, 'Hey, me.'

**Dr ASHBRIDGE:** One of the points is that even if you can create a very small number of cases which in the presence of adequate palliative care manage to slip through the net, then is that the basis for creating a law which pervades the whole of society?

**Mr POOLE:** That is the essence of the argument; the argument really is, either you believe in the sanctity of life, or the right of the individual.

**Dr ASHBRIDGE:** Not only the sanctity of life, but I would extend it further than that, and I would think that ...

**Dr GIBLIN:** The sanctity of the community.

**Dr ASHBRIDGE:** Yes; for example there are community values which we have to operate under, and this comes from someone who does not have a religious background but I believe that we have to have some framework to operate under and I think if you start talking and creating laws for a very small percentage which change the whole fabric of society ...

**Mr POOLE:** But we do; almost all our laws are addressed at a very small percentage of the community. I mean, the crime of murder is not there for the wider section of the community. The crime of murder is there because there is a .0002% of people in our society who kill people.

**Dr WEERAMANTHRI:** But there is no corresponding damage to the common good by introducing a law that helps murderers, though.

**Mr BROMWICH:** This is the point.

**Mr POOLE:** I am not arguing the case and I am listening and giving you scenarios.

**Dr?:** I know, and a fair comment.

**Mr BROMWICH:** The old maxim of heart keepers make bad law does have a relevance here, and that other maxim ? **Latin????? -** help for the people is the highest law - is as we have said, the relevant thing here. This Act, this bill if it becomes an Act, will damage the practise of medicine for everybody.

**Mr POOLE:** I hear you say more than that; really it will damage the fabric of our society.

**Mr BROMWICH:** Indeed yes.

---

**Dr GIBLIN:** There was one thing about medical competence. I had a lady ask me the other day if she was mentally competent, could she choose the mode of her death? And I said, 'What on earth do you mean?' And she said, 'Well, I always wanted to die by firing squad; does that include ...

**Mr POOLE:** We are ahead of you.

**Dr GIBLIN:** She is medically competent.

**Mr POOLE:** Yes, we are ahead of you such that we have already as I said, now hang on, does this mean the doctor suddenly pulls out a .45?

**Dr WEERAMANTHRI:** You would have to say, why not?

You would have to say, what is it that supports this bill that should not support you ...

**Mr POOLE:** Yes. The normal thing of course in a situation like this if the bill did become law, that would be determined by regulation I would suggest, and the schedule already decided.

**Dr GIBLIN:** You would infringe the individual right to die by whatever means they chose in that sense.

**Mr POOLE:** But at the moment in the Northern Territory attempted suicide is a crime; suicide itself of course is not.

**Mr BROMWICH:** Yes, that is the case in many jurisdictions.

**Mr POOLE:** But the reason of course is to stop people jumping off high buildings and landing on the unfortunate people beneath them.

**Mr BROMWICH:** And also aiding and abetting is a crime.

**Mr POOLE:** All right, thank you very much gentlemen, ladies, for your time. I appreciate it.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARING**

Wednesday 29 March 1995 Opened: 17.40 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative: NORTH AUSTRALIA ABORIGINAL LEGAL AID SERVICE

Ms Jenny Hardy

Mr Harold Wilson Jnr, President, Peppimenarti Community Council Inc

Mr Michael Walker, CDEP Supervisor, Milikapiti

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

---

**Mr POOLE:** I welcome the following witnesses on behalf of the North Australian Aboriginal Legal Aid Service, who are appearing before the committee to give evidence today: Ms Jenny Hardy, Harold Wilson Junior and Michael Walker.

We do not require you to take an oath or anything like that but I will ask you to remember that any information you give to the committee must to the best of your knowledge be truthful. We have changed the rules which we normally have for people who give evidence to a parliamentary committee. Normally, you cannot talk about it and it cannot be publicised anywhere. In this particular forum, however, we are allowing the information to be publicised. That is because of the interest of the general public and the fact that we want other members of parliament to be able to read what you have said and to understand all the questions that have been asked about this particular bill.

If you want to tell us anything that you want kept confidential or private, all you have to do is ask us to consider that before you tell us. So if you want to make a private comment, please just say: 'I want to keep this as a secret amongst ourselves'.

Everything you say today is being recorded and these are the microphones here. A transcript will be typed up and you will get a copy of that transcript. When you speak, we would like you to start by giving your name.

We have been asking people to start off by saying what they would like to say to the committee. When they finish talking, we have been asking questions. Is that the way you want to handle it? Are you happy with that?

**Mr WILSON:** Yes.

**Mr POOLE:** All right. It is all pretty informal. Please say whatever you like and we will see if we can get a two-way conversation going.

**Ms HARDY:** Okay.

**Mr POOLE:** Thank you very much for finding the time to come and talk to us.

**Ms HARDY:** Thank you for the opportunity and the invitation to come and speak today. Perhaps I will start by talking about what we have done about this at NAALAS. Then we can start to address the issues that are in the written submission which I understand you all have.

We started talking about it within the office, discussing Aboriginal cultural views on suicide and euthanasia. People indicated that it was not something that they were even aware of. About a week later, there was a meeting of the NALAAS council and it was raised again. The 5 regional members on the council indicated that in their understanding, euthanasia and suicide were not known within the culture. They were also of the view that Aboriginal people were very worried and concerned about the bill and the information they were getting about it. They needed more information.

---

The regional members agreed to go back to their communities and speak to people about what they thought about it. To make that a little bit easier, I prepared a very short piece on what the bill actually did, leaving aside most of the details. I am very happy for the committee to have copies of that if they wish, so that it is clear that there was no misinformation, emotive language or anything else. It set out the bare bones in a language that was fairly easily understood by people. That is how we did the consultation.

**Mrs BRAHAM:** Can we ask what communities?

**Ms HARDY:** Harold is from Peppimenarti and Michael is from Milikapati. We spoke to Milingimbi and Ramingining as well and we also have a member from Yirrkala. I spoke to him last week and I understood that they were organising a community meeting some time this week. I am not sure whether that has happened but I understand that the committee will be visiting Nhulunbuy and Yirrkala next week and hopefully you will get the views of the community. Other than the comments of the regional member at the council meeting, we have not yet had feedback on their position.

We have not consulted widely within urban Aboriginal communities. The main reason for that was that the politicians were saying that they were going to canvass opinion within their electorates. From our discussions, it is clear that there is as much disagreement among the urban Aboriginal population as there is among the non-Aboriginal population. That would be probably the fairest way of saying it.

I suppose the crux of our submission is that there has not been nearly enough time for consultation. It is very difficult to deal with something like this where there is so much emotion involved. There is a lot of concern and perhaps fear in Aboriginal communities about the bill and its possible effects. It is terrific to hear that the committee is about to go to Aboriginal communities and talk to people. However, I understand that you have about a week in which to travel to about 5 communities. It will be a very big task to canvass people's views while you are there.

I guess the crux of our submission is to ask you to slow down so that we can have more time on this. It is a matter that people are concerned about and I think there needs to be time to allay the fears that are out there. I think that many fears could be allayed by having the right information and enough consultation about it. But that is certainly not possible within the month it took to get this submission prepared and it is certainly not possible within 3 months. I think that perhaps a year would be a realistic target. That is the crux of it all. Harold, do you want to talk about the fears that people have in the communities?

**Mr WILSON:** One of the fears is that most Aboriginal people cannot understand English properly and cannot read and write. They sometimes say yes when they should not say yes and no when they should not say no. It is difficult. For most Aboriginal people, suicide is not a word. I do not think that it exists in Aboriginal culture. No one person would want to tell somebody to kill him or ask somebody to do something to get rid of him because he is under a lot of stress from pain.

---

**Mr POOLE:** Do you yourself understand what they mean by euthanasia.

**Mr WILSON:** To an extent, yes.

**Mr POOLE:** What do you think euthanasia means?

**Mr WILSON:** The drug itself or ?

**Mr POOLE:** The word 'euthanasia'.

**Mr WILSON:** No.

**Ms HARDY:** Do you understand what the bill is about?

**Mr WILSON:** The bill. Yes, I understand.

**Mr POOLE:** I guess we could spend a lot of time talking about what the bill means today. Really, we are more interested in what you and your people think about the bill.

**Mr WILSON:** If we are talking about an old Aboriginal person, he is going to die anyway.

**Mr POOLE:** But what this bill is talking about might not be an old Aboriginal person. It might be a young Aboriginal person who is very sick. The doctor might say: 'Look, sorry, I cannot do anything to help you. You will be dead next month or whatever'. It might be because of kidney failure or any other illness. 'It is going to be very bad. You will be very sick. If you want to, we can put you to sleep and help you die peacefully rather than painfully'.

**Mr WILSON:** Maybe I should have said most Aboriginal people cannot read and write.

**Mr POOLE:** Looking at the letter and the submission I wonder whether, as far as the bill is concerned, there should be something that stops the doctor from using it with Aboriginal people unless they have had an interpreter to explain everything properly.

**Mr WILSON:** It should be explained properly, yes. But in Aboriginal culture, you just cannot kill anyone like that.

**Mr POOLE:** I am not saying that this bill will become law. That is what the parliament has to talk about. If it becomes law as it is now, it will only be applied to people who say: 'I am very sick. I am very much in pain and I want to die now. Please help me'. If you do not say that, nothing will happen. You just go on until you die normally, no matter how long it takes.

**Mr WILSON:** Even if the person did ask the doctor to give them a needle so that they could die and not be in pain any more, it still reflects on the people.

---

**Mr POOLE:** Sure. That is the point you make here about other people in the community, who might say: 'We are going to die too.'

**Mr WILSON:** Yes.

**Mr POOLE:** As a committee, we probably agree with your sentiments as far as wide discussion is concerned. It has not taken place in the rest of the Northern Territory community either. That does not mean that the law will not be passed or will fail because of that.

We will discuss this as a committee but I personally accept the rationale behind your submission. The least I would want would be an amendment which states that it cannot be applied to people who do not understand it. That does not only apply to Aboriginal people. It can apply to some of the older people who have come from other countries, particularly some of the new groups such as the Vietnamese people who speak a different language and maybe do not understand it.

**Ms HARDY:** You say that this procedure will only be used when a person puts their hand up and requests it to happen. One of the things that happens when you are sick is that the doctor will give you the available options. It may be that a doctor will say to a patient: 'This is an option for you'. We are concerned that it be done with the best of intentions. I am not suggesting that there is anything mala fides about the way that would be done but that option would be put to people. Our concern is that people will not necessarily understand what is being put to them. Is that what you are talking about, Harold?

**Mr WILSON:** Yes.

**Mr POOLE:** I think we can fix that with amendments. However, it is obviously something that we will debate in the Assembly anyway.

**Mr WILSON:** With an interpreter?

**Mr POOLE:** I think that is the only way you could fix it. You could not achieve it with a piece of paper. You would need to make sure that, if someone said they wanted to do it, someone would be brought in to make sure that everything was properly understood.

**Mr WALKER:** I reckon they should get good attention when they go to hospital too. When a doctor wants to give them a needle or something, they should have someone to explain that too.

**Mr POOLE:** They do not understand.

**Mr WALKER:** Yes. They do not know what they are signing. It is not only old people but young people too. It can be anybody.

**Mr POOLE:** Particularly if they have lived in the bush all their lives.

5

---

**Mr WALKER:** That is right, and they do not have much schooling.

**Mr WILSON:** I am a bit concerned when you start having interpreters present when you are discussing it with that sick person. Payback can come in on that and that is serious.

**Mr POOLE:** You mean ...

**Ms HARDY:** To the interpreter.

**Mr POOLE:** To the interpreter but I guess there is a chance that somebody who is interpreting might be involved in payback anyway.

**Ms HARDY:** It could also apply to the doctor.

**Mr WILSON:** If he was in a rural area, he could be knocked on the head.

**Mrs BRAHAM:** Does suicide happen amongst Aboriginal people?

**Mr WALKER:** Very seldom.

**Mr POOLE:** Yes, it does happen occasionally. Usually it is because somebody is drunk or something.

**Mr WALKER:** I reckon that the families should be involved in it too, not just the doctors themselves.

**Mr POOLE:** At the end of the day, if it becomes law, the family will be involved even in white society. That is obviously very important for Aboriginal people.

**Mr WILSON:** The immediate family or ...

**Mr POOLE:** Yes.

**Mr WILSON:** In Aboriginal culture, it does not just mean the immediate family. It is the extended family too and if the extended family was not consulted or notified ...

**Mr POOLE:** I do not pretend to be an authority on Aboriginal culture but having lived up here for a while and spoken to a lot of people, I would think that very few people in the Aboriginal community would take advantage of this law. They would just say that they do not want to do it because of the cultural problems associated with it. I cannot see how you could sit down with a hundred people and get them to make a decision which says: 'That is okay. He can have a needle'. I do not think that will happen.

**Mr WALKER:** No. I reckon the thing should be extended a bit longer.

---

**Mr WILSON:** What I mean is that the immediate family might agree to a person being injected. But if the other family has not been ...

**Mr POOLE:** Maybe his wife's family or something. It is pretty complicated, isn't it?

**Mr WILSON:** It is complicated.

**Mrs BRAHAM:** So you would probably never get agreement anyway.

**Mr POOLE:** No, I do not think so. I think maybe that is a point that has to be raised in the bill.

**Ms HARDY:** I think you suggested it should be excluded with Aboriginal people or something. That really cannot be done.

**Mr POOLE:** No. But you can certainly put a clause in the bill which covers the language difficulties.

**Ms HARDY:** Yes, that is possible.

**Mr POOLE:** There could be a clause stating that, in the case of an Aboriginal person or a nonEnglish speaking person, the matter must be discussed with an interpreter present and the family must be fully informed.

**Dr LIM:** How do you overcome the problem of a potential payback? For instance, you may have gone through what you think is due process with the extended family and with an interpreter present. The patient then having been accorded the privilege of euthanasia, repercussions occur later on. What mechanisms can be used to at least protect the interpreter?

**Mr WALKER:** I do not think the interpreter will be affected. It is just the family of the person. If one family has been notified and the other has not, it is just between the two families.

**Ms HARDY:** You occasionally see it happen now. There will be a murder at one community and several deaths will occur as a result of payback. It goes on for some time. This could be viewed in exactly the same way.

**Dr LIM:** I am pretty ignorant about Aboriginal life and culture. I used to think that, in the old days when a member of the tribe is too old and can no longer help the tribe, they actually went off into the desert by themselves. Am I right in saying that?

**Ms HARDY:** As I understand it too and these guys will be able to answer that better than I there are people who decide that they have had enough and they consciously make their decision.

---

**Ms HARDY:** I am not sure. Is that right?

**Mr WALKER:** People die by natural causes. That is nothing.

**Mr POOLE:** I mean in the old days, when the people in central Australia were walking around the country getting food, if an old person just could not keep up, they would just stay behind. The other people would leave them because they were very old and because they were really dying of old age and natural causes.

**Mr WALKER:** I do not think that I have heard of that before.

**Mr POOLE:** No?

**Mr WALKER:** No.

**Mr WILSON:** Does that happen now?

**Mr POOLE:** No, I am not suggesting that it happens now.

**Mr WILSON:** That is another question really because, you know, we have a lot of murder on Aboriginal society. Older people more or less did not ...

**Mr POOLE:** I am talking about a long time ago. Not 10 or 20 years ago but 50 or 100 years ago.

**Mr WILSON:** I do not think they do it now.

**Mr POOLE:** No, I do not think so either. Not too many people now are moving around all the time hunting anyway.

**Mr WILSON:** That is right.

**Mr POOLE:** Most of them are living in settlements.

**Mrs BRAHAM:** What we seem to be hearing is that it perhaps could happen if there was full consultation. You are not really opposed to the bill. Is that what I am hearing?

**Mr POOLE:** No, I do not think you are hearing that. I think you are hearing that they have great reservations about the bill ...

**Mrs BRAHAM:** Because of language, because of payback, because ...

**Mr POOLE:** They certainly would not even consider it unless there was adequate explanation of the bill in their own language at the time and it was done with family consultation.

---

**Ms HARDY:** The point is that it is difficult to present a view on this because we just have not had time to consult widely enough to know exactly what people are feeling. I mean, Harold and Mickey have consulted fairly widely within their communities but they are only 2 of many in the Northern Territory.

**Mr WALKER:** We were talking about the bill being put into different languages so that people can understand. We were talking about that at our office. If the committee can do that ...

**Mr POOLE:** I think probably what you have to do is to get a video of some kind, get somebody actually talking rather than having it put on bits of paper. Get it out to the communities so people can actually sit down and listen.

**Mr WALKER:** But you have a lot of different languages to ...

**Mr POOLE:** Yes but the same problem applies to printing it. Lots of people cannot read at any rate. It is better to have people talking.

**Mr WALKER:** You have Alice Springs and up here Daly River and Peppimenarti, and different places like that.

**Mr POOLE:** With the greatest of respect, if the bill should happen to go ahead and I am not saying that it will this committee would certainly want to make sure that there were some provisos to ensure that it could not be applied to anybody who did not understand its provisions.

**Ms HARDY:** Sometimes the difficulty is to know whether people understand or not. It comes up in our work quite a lot. You ask a client: 'Do you understand English?' Quite often the person will say yes. However, it becomes clear when you start asking them about specifics or technical things that they do not understand. That is the major concern. You have to make decisions about when to bring in an interpreter and in what sort of cases.

**Mr POOLE:** I suggest that there could be an amendment to the bill which required the doctor to be able to prove that the person was competent in English, that English was properly understood and so on. Particularly among GPs who work with

Aboriginal people fairly regularly, I doubt that doctors will be dashing off trying to give them a needle.

**Ms HARDY:** No, I am not suggesting that at all. What I am saying is that there is a possibility that the option will be put to an Aboriginal patient who will say: 'That's sounds like a great idea and my pain will stop'. The problem is that the person may not necessarily have understood that the decision will mean the end of their life.

**Mrs BRAHAM:** Particularly if they have come from a community to the Royal Darwin Hospital.

---

**Ms HARDY:** Their family may not be present to help them make that decision. They may be on their own or they may only have a couple of people with them. How do you make sure that person understands?

**Mr POOLE:** I think the only way you do it is through an amendment to the bill which says that this is the way it has to be done.

**Dr LIM:** Even with interpretation, there is the question of the nuances of language. If I wanted to describe this concept in Chinese, I would have to get out of my Anglo way of thinking and go into a Chinese way of thinking so that I could describe it in Chinese concepts. I am sure that the same thing would apply to Aboriginal people and even from one tribe to another.

**Mr POOLE:** From what little I know, I can see that there are all kinds of cultural problems with it anyway.

**Ms HARDY:** That is right.

**Mr POOLE:** I think we just have to take the attitude that somehow the bill just does not apply to them. The only way to do that is through an amendment.

**Mr STIRLING:** If the terms 'competence' and 'competent' in the bill were defined properly to incorporate use and knowledge of language, that would be part of the understanding. 'Competence' means that the person has understood. If there are language barriers, 'competence' needs to be defined. I think there will be amendments to the bill, such as in relation to the definition of 'competence'.

**Ms HARDY:** Later in the submission, we discuss the concept of the person being considered to be competent before they can use this. That is something that comes up all the time under the mental health legislation. With many of our clients, a misdiagnosis is often made about whether they are competent or not, or mentally ill or not. This occurs because of misunderstanding of cultural factors, the way in which people deal with figures in authority and all those sorts of things. It happens all the time and it is an issue. I am not sure that you can necessarily cover that with language. Perhaps it is a matter of crosscultural training. I am not sure that that would go a long way towards handling it. I am not sure what the solution is.

**Mr POOLE:** All right. Are there any questions? Is there anything else you would like to say to us?

**Mr WALKER:** Another thing we want to think about is what happens if the doctor brings up a paper for the person to sign. We want to know what happens if the sick person cannot do it. Can one of the family do it? That would not be right.

**Mr POOLE:** I think we all agree, even with the white community, that we have some difficulties about other people signing.

---

**Mr WILSON:** I have a problem with that too.

**Mr POOLE:** I think we all have a problem with that.

**Mr RIOLI:** So will the rest of the family, too.

**Mr WALKER:** I am saying that, if you are a person who does not understand what his rights are ...

**Mr POOLE:** I hear what you are saying and we agree with it. It is one of the grey areas of the bill. I think it needs to be clearly spelled out that other people cannot sign and if the person does not understand what they are signing ...

**Mr WALKER:** I reckon that people would also be wild if the doctor could sign it.

**Mr POOLE:** At the moment you have to have two doctors: the doctor who is looking after the person and another doctor. The other doctor talks to the first doctor, looks at the patient and talks to the patient. Two people have to be involved. However, if the person does not speak or understand English and written language, I do not see how you could ever accept that as an authority. I think you would just say: 'Sorry, I cannot do it'.

**Ms HARDY:** I would hope so.

**Mr POOLE:** Yes. These are the questions we will be asking the parliament. It is a very grey area. I think everybody would have reservations about somebody else saying: 'Do not worry; I will sign on their behalf'. It is not the same as taking their cheque book.

**Mrs BRAHAM:** There are probably more safeguards in Aboriginal communities than in white communities. We are not going to have the families jumping up and down if that happens.

**Mr POOLE:** All right. Is there anything else you would like to raise with us?

**Ms HARDY:** I think the other points about the terms of the bill are included in this submission. I do not need to talk about them other than the mechanism for a coroner's inquiry. That is important. If families do not have an opportunity to find out what happened and things like that, it will again cause problems within the community. Dr Lim asked before about being able to perhaps have some mechanism to avoid payback consequences. One possible solution may be to have full and open inquiries if and when these procedures are ever used.

**Mr POOLE:** All right. If you think of further things you want to put to the committee, please feel free to do so. Although we have passed the closing time for written submissions, we are more than happy to discuss the issues further. We do not all have to be involved in the meeting. Three members can meet with you as a subcommittee if you have

---

people who want to talk to us. There will of course be an opportunity at the end of next week. We are travelling around and we are going to be talking to several communities up here, so we are happy to talk to other people too.

**Mr WILSON:** Are you likely to go out to the Daly region?

**Mr POOLE:** Not at this stage. If we were asked to go out there and talk to them, we certainly would look at it. We have a commitment already to talk to 3 or 4 communities up here. Ideally, we would like to talk to all the communities, but we do not have time to do that and not everybody has expressed an interest in talking to us. That may be because they do not understand what is happening.

Thank you very much for the effort you made in coming to talk to us about this. Hopefully, we will be talking some more. Thank you.

## select COMMITTEE **ON EUTHANASIA**

## PUBLIC HEARINGS

## HERMANNSBURG

Monday 3 April 1995 Opened: 10.45 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives:

Mr Gus Williams, President

Ms Gail Blenner-Hassett, Sister

Ms Helen Stewart, Senior Health Worker

Ms Emily Cox

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

1

---

**Mr WILLIAMS:** Mr Eric Poole is the chairman of the euthanasia committee. The members are Lorraine Braham, Dr Richard Lim, Maurice Rioli and Syd Stirling. Pat Hancock is the secretary. Roslyn Brophy and Dave Nason are here too. Now Mr Chairman, I hand over to you.

**Mr POOLE:** Thanks, Gus. We will try to keep this as informal as possible. We are just moving around the countryside. We go back to Alice Springs to talk to people tonight and tomorrow we fly to Tennant Creek. We do the same thing there before going on to Katherine and Nhulunbuy and then back to Darwin. We will also visit some of the communities as we go up the track and further north to talk to people in the bush. This committee has been empowered by the parliament to talk to people and listen to what they have to say so we can then tell all the other members of the parliament about the views of people on this idea of euthanasia.

We really did not come here today to do the talking. We really came here to do the listening. If you have some thoughts, please by all means talk to us about them. We are recording everything that is said for the Hansard record. That is so all other people can read it. All the other members of parliament can read what people have to say. So when you want to talk it is important that you tell us your name so it will be on the tape recording, okay?

**Mr WILLIAMS:** I forgot to mention that another member of parliament, Mr Bell, is here. I am Gus Williams and I do not really know much about this euthanasia thing. Maybe one of you members actually need to explain it to us a little bit. Then you will get some feedback. We do not hear a lot about what is happening. Not all the people read, listen to radio or watch telly.

**Mr POOLE:** All right. It is important that you realise that this committee will not go back to the parliament and say that we are either in favour or against the bill. The idea is just to collect the information and to write a report with a summary of what the committee sees are the good things about the bill or the bad things about the bill. We will present the report to the parliament and then the members will debate the bill and vote on it.

Basically, Marshall Perron introduced what they call a private member's bill. This bill has not been put together by the CLP or the ALP. It was decided that the members of the parliament can vote for it as individuals. It might be that some ALP members will vote for the bill and some ALP members will vote against the bill. The same applies to the CLP; some members will vote for the bill and some will vote against the bill. It really has nothing to do with the political parties. It is a bill that people will vote to pass or not pass on their own conscience, what they feel.

In essence, the bill has been designed by Marshall Perron to allow people who are very sick and suffering pain and distress to say to their doctor: 'I am going to die at any rate and I want you to help me die'. A sick person can say to their doctor: 'Look, you have told me I am going to be dead in 3 months or 6 months because I have cancer or whatever. The pain is very bad. I want you to help me go to sleep and, in effect, commit suicide'. That doctor has to talk to another doctor and the two of them have to agree firstly that the person is dying and will die within 12 months no matter what they do. Secondly, they have to agree that the person's pain and suffering is such that the person should be allowed to commit suicide.

2

---

Whether the bill is passed depends on what people think about that idea. There are other bits associated with the bill. It is not a particularly long bill. We have copies if you want to read the bill.

**Mr WILLIAMS:** Yes, we would like a copy.

**Mr POOLE:** Do we have a copy available?

**Mrs HANCOCK:** I did not bring them out.

**Mr BELL:** I have one. Unfortunately it has my notes on it but you are welcome to have it.

**Mr POOLE:** We have been hearing what doctors and nurses and other people think about it. Some religious groups are very strongly against it. Other groups of doctors say that it should be allowed. We are here today to listen to what you think about it.

**Mr WILLIAMS:** Chairman, when you explained this euthanasia, you mentioned the 2 doctors but you did not mention family members coming in to prove what the person wants.

**Mr POOLE:** Gus, the same comment was made to us by some Aboriginal people who appeared before the committee in Darwin last week. There is no provision in the bill to allow other people to make the decision for you. It has to be the individual. They are the only person. For example, if you were my son and you had been injured or were dying, I could not go to the doctor and say: 'Yes, I think it would be best for Gus to be put to sleep'. You have to do it yourself.

**Mr WILLIAMS:** I might request that. But there are hundreds of families who might want to say no. Even if one person says that they want to pass on, I do not think that the other family would agree. It is not just one person who is concerned; it is the families too.

**Ms STEWART:** My name is Helen Stewart. I am a senior health worker. It is not only the close family. Aboriginal families are extended families too, you know. We have to look at them. Families are the main people to agree with that. It is very hard for Aboriginal people. People have to go and talk to different groups of families. It is also very hard for the patient to say yes. It is not part of our traditional ways to say yes to this.

**Mr POOLE:** The bill is not really there as a matter of convenience. It is there for somebody who is really suffering very badly, who is very sick and has no chance of coming good.

**Ms COX:** What about people are in comas because of an accident?

**Mr POOLE:** It would not apply. You must have the ability to say: 'I want this to happen to me'. Your family cannot make the decision. People in comas are already covered, in effect, by the Natural Death Act. All states in Australia have a Natural Death Act.

---

**Mr WILLIAMS:** Can I ask Dr Lim to talk about that from a doctor's point of view?

**Dr LIM:** In what sense, Gus? I am not sure.

**Mr WILLIAMS:** Following on from what Mr Poole said, what is your interpretation as a doctor?

**Dr LIM:** Up to this point in time, I have not come out publicly to express which position I hold on euthanasia. However, from a doctor's point of view this is what would happen. Suppose a person who is terminally ill and has only 12 months to live is suffering a great deal of pain and distress, and says to a doctor: 'Look doctor, I cannot put up with this any more. It is too bad and I want it to stop'. The only way the doctor can stop it is by putting this person down. The doctor has to be completely convinced that the person really wants to do that. Quite often, the doctor will also talk to the family. For example, in a hospital situation you speak to a lot of people in the family around the bed and discuss the whole issue. Some families might say: 'Yes, this is the way to do it'. Others might disagree.

If the family agrees and remember that that is not part of the bill because only the patient decides the doctor needs to refer the patient to another doctor. That second doctor has to agree that the person has only 12 months to live because of the terminal illness and that the patient is not confused but is really clear about the decision. Then, and only then, can we sign the form to say: 'Yes, the person is clear in the mind that he or she wants to have this done to them'.

After that, the patient signs the form. It is then up to the patient to decide when it should happen. The patient can change his or her mind at any time. With the bill as it stands, the patient can say halfway through the injection: 'Hang on, I do not want it. You have to stop!' The patient has the right to do that, okay? So that is what the bill really talks about. Does that explain it for you, Gus?

**Ms BLENNER-HASSETT:** My name is Gail Blenner-Hassett and I am a sister here. My concern is where do you get the 12 months? I mean, God is the only one who knows. I have seen doctors tell somebody that they have 3 months to live and 3 years later they are still alive. I have a problem with that time span. I also have a problem that the family is not consulted.

Euthanasia has been a big issue as I was saying before. In Victoria, it has been on and off the political agenda for many years. It is something that is quite dear to me, having worked in palliative care. Anybody who works in palliative care knows that these things have been going on for many years and that lethal doses of morphine are given. I do not have a problem with the bill if it is a matter of removing the possibility of a doctor being prosecuted for doing it. That threat does need to be lifted.

The issue of being of sound mind is difficult. How do you determine that somebody is of sound mind? I also have a little bit of a problem that there is no consultation with family

---

and the family has no right as far as signing goes. I mean, what do you do in cases of Alzheimer's, where a whole family and all those carers are suffering? The person might not be suffering that much but the family has no right to sign anything. I do not feel that there is any provision for that ...

**Mr POOLE:** The bill is intended to exclude that area. The proponent of the bill, Mr Perron, has said on many occasions that he has tried to narrow the range of people to which the bill applies in order to avoid those sorts of arguments. Nobody makes the decision except the person concerned. It is not a bill that allows families to have family members put down for whatever reasons. I am trying not to advocate one view or the other but simply to respond to questions.

**Ms BLENNER-HASSETT:** I have quickly read through the bill and I would like to add that I do not know how appropriate it is to Aboriginal communities. It seems to me that the majority of the deaths occur very quickly. It is not like a society that I am used to in which people live into their 70s and 80s and develop diseases such as cancer. Basically, the bill seems to be for somebody who is told: 'You have terminal cancer; it has spread'. I have not been here a long time but I would imagine that it is not terribly pertinent to Aboriginal communities. People do not get to that stage.

**Dr LIM:** Gail, in the case of other illnesses such as terminal renal failure, the prognosis could be less than 12 months. I agree with you that cancer is less likely to occur among Aborigines because their life span tends to be a lot less than that of the mainstream population but illnesses such as terminal renal failure are quite prominent. Would that be a reason for using this?

**Ms BLENNER-HASSETT:** I see that in the context of the active and passive euthanasia that we would previously have talked about, such as in turning off machinery. If you do not have that piece of machinery, you are not going to live. That is the case with renal failure.

**Dr LIM:** Yes.

**Ms BLENNER-HASSETT:** A person has the right to say: 'I do not want to move out of my community. I do not want to go to Alice Springs and be on that machine for 3 days a week'. In Aboriginal communities, that would be a family ...

**Dr LIM:** Yes.

**Ms BLENNER-HASSETT:** But according to the legalities under this bill, only the person involved is a signatory.

**Dr LIM:** Yes. To develop this a little bit more, let us say that a person with terminal renal failure has less than 12 months to live and has been advised by the specialist that: 'You have to come to Alice Springs to use this machine. Otherwise your chance of survival is very limited'. The person says: 'No. I am not going to go. My family says I should not leave this

---

community'. That is fine. So the person gets sicker. There comes a stage when the person says: 'I cannot put up with this any more. I cannot live another day'. Although if left alone the person might live for another 3 or 4 months, he says: 'I cannot live another day. Please do something. Please stop it for me'. That is the situation we need to look at.

**Ms BLENNER-HASSETT:** I would like to hear the views of the community. As a nurse, I personally do not have a problem with that. I do not have a moral problem with that.

**Dr LIM:** Would you then have euthanasia given to this person? Would you euthanise this person because they cannot put up with it any more?

**Ms BLENNER-HASSETT:** Yes, I would. I could. But I think it would have to come from families. This is where the ...

**Mr POOLE:** Gail, you said earlier that you are aware that this sort of basically goes on any rate. It has been put to the committee that surely it would be better to decriminalise it so that at least then the community would be in a position to know who, when, where and how many. Many doctors, including some who are against the bill, have actually said that it all depends on the intent.

**Ms BLENNER-HASSETT:** Exactly.

**Mr POOLE:** When you give somebody an overdose or a very heavy morphine injection to relieve pain and suffering, it is the intent that is the important thing. The intention is to relieve the pain and suffering even though the side effect might be that they die. Other people, of course, would disagree and say: 'That is euthanasia'.

**Ms STEWART:** I had one case in which a brother and sister were suffering. They both had cancer. I brought my brother back. Even though he suffered a lot, once a person feels home, they ...

**Mr RIOLI:** Do they think about ending their life or do they just want to be with their family?

**Ms STEWART:** I think most of all they want to be with the family.

**Mrs BRAHAM:** It is an emotional topic.

**Mr WILLIAMS:** A lot of families request that they come back. A lot of people have asked me to come back. It is only a matter of a few hours, not weeks or days. I mean, she is my cousin from my father and my mother. It is upsetting. I saw my cousin come back. It was only a matter of a day and he was gone but he wanted to pass away here.

**Mr POOLE:** I would think that the bill really would not apply to those sorts of things. A doctor would want to comply with a patient's request to return home if he was going to die in a couple of days.

6

---

**Mr WILLIAMS:** It happens that some of my people, Aboriginal people and relations and this even happened recently might request that machines be disconnected. Is that the same thing, Dr Lim?

**Dr LIM:** No, it is not the same thing. This bill is not about disconnecting a machine. It is about actually giving an injection, or possibly several injections, to stop them. It is a bit different.

**Mr WILLIAMS:** I saw some examples of euthanasia during that program about the flying vet. That was with animals.

**Ms BLENNER-HASSETT:** That has always been an issue. When I was down south I used to feel that we have the right to be decent to our animals, to put them down when they are in great pain. It was always a bit of a bone of contention. People are writhing around in bed in absolute agony and you just wait every day, hoping and praying that they will go. Yet we don't actually have the right to be kind

**Mr POOLE:** The subtle difference is that the animal does not have the opportunity to say: 'Hang on. I might be suffering but I would still like to hang around a bit'.

**Mr WILLIAMS:** But you sometimes get the feeling that they are talking to you.

**Ms BLENNER-HASSETT:** A lot of people see a euthanasia bill as a right to kill. On a very quick reading of this bill, however, it seems that you are really only talking about a very small minority of people who would have the right to this.

**Mr POOLE:** Who would qualify?

**Ms BLENNER-HASSETT:** Yes.

**Mr POOLE:** That is probably one of the bones of contention in the argument. Some people see it as a foot in the door. People who oppose the bill are basically saying: 'Hang on. This is just a start. Today it is voluntary; tomorrow it will be involuntary'.

**Ms BLENNER-HASSETT:** Another comment has been made to me and it may have also been made to you. Some people see this as a political cop-out in order to spend less money on health care for Aboriginal people. It has to be made clear to the people that they will not be denied access to expensive treatments.

**Mr POOLE:** I am sure that Marshall would say that there is no intention of that. The bill is not aimed at the elderly. It is aimed at people who are terminally ill. They might be 20 years old. I would suggest that people of advanced years who had Alzheimer's for example, would not qualify. The doctor has to be able to say that the person is of sound mind.

7

---

**Mr BELL:** I would like to pick up on Gus's earlier comment about life support systems. I is important that people be aware that in 1988 the Legislative Assembly passed the Natural Death Act, which authorises the withdrawal of what the act refers to as 'extraordinary measures' like life support systems. If somebody depends on an artificial mechanism to stay alive, the law already states that it can be withdrawn.

**Ms BLENNER-HASSETT:** We have had a very recent incident of that. We had a funeral last week.

**Mr WILLIAMS:** Yes. My sister-in-law is sitting here. It was one of her cousins.

**Ms BLENNER-HASSETT:** I think a lot of the family had trouble understanding that he would not live without that machinery.

**Mr STIRLING:** Gus, do you think that there is much understanding of this among people in the community?

**Mr WILLIAMS:** Not really. Not the euthanasia bill. We do not hear much, you know. This is the first time I have seen the bill. We did not get a copy until recently. We have not really had a chance to talk about it. Maybe the bill was posted to us.

**Ms HANCOCK:** I sent the original letter to you when I sent letters to all Aboriginal communities. A copy of the bill was enclosed with various notes. It was about a month ago.

**Mr WILLIAMS:** Oh, right.

**Mr POOLE:** But everybody accepts that the majority of the community has not seen the bill. It is the same in Alice Springs. A lot of the members have sent bits of paper around. You could do it quite easily in Alice Springs. It is not so easy for Neil or Maurice.

**Mr WILLIAMS:** I think we have learned over the years to become involved in the outside world. Most of us have got used to receiving things like this so that we can comment on them.

**Dr LIM:** Gus, can I ask a question about Aboriginal culture? I do not understand it well enough. Does the concept of suicide not wanting to live any more exist in Aboriginal culture?

**Ms COX:** Can you say that again?

**Dr LIM:** I am talking about the concept of suicide. For example, in Japanese culture people commit suicide as part of their culture. They might do it if they fail an exam or bring shame to the family. Some societies do not have suicide as a concept in their culture. They do not even think about it. Is that the case with Aboriginal culture?

**Ms COX:** No. See, we have to worry about being paid back too. If Uncle Gus decides that he is going to kill himself, I have to worry about payback for that too.

**Dr LIM:** If you give your permission?

**Ms COX:** Yes.

**Mr WILLIAMS:** That is still very strong in our tribal culture. It is part of our law. It is like our constitution. Instead of being taken over by the white constitution, we would like it back.

**Mr POOLE:** If you go back in history, there are lots of examples in nomadic lifestyles where the elderly were left to die because they could not walk any more or could not continue.

**Mr WILLIAMS:** Yes, but they did not leave those people to die alone.

**Mr POOLE:** No. But you could say that that is a form of euthanasia.

**Ms COX:** But the people were looked after. They were not left to die on their own.

**Mr POOLE:** Sure. Marshall's intention with this bill is not to just give someone an injection and walk away saying: 'See you around'. He is trying to sell the bill in a caring sense. You only do it because people are suffering intolerably from pain, not simply because they are a bit depressed.

**Ms BLENNER-HASSETT:** Could there be payback if the request has come from the person who is actually getting the lethal injection?

**Mr POOLE:** That has been raised. There could be a question of payback for the doctor.

**Ms BLENNER-HASSETT:** Exactly. I would think that it would fall more on the health provider or whoever actually administered the lethal injection.

**Mr RIOLI:** You are Gus's wife, are you?

**Ms COX:** No. He is my uncle.

**Mr RIOLI:** Your uncle, right. Are you saying that, if Gus was to put himself down, his wife might be blamed for not stopping him? Is that what you are saying?

**Ms COX:** Yes.

**Mr WILLIAMS:** Or my brother.

**Ms COX:** Somebody will get payback for it.

**Mr RIOLI:** The brother might blame the wife for letting him do it. Is that what you are saying?

---

**Ms COX:** Yes.

**Mr WILLIAMS:** Or the brother or the children.

**Mr RIOLI:** Or the children or the sons.

**Mr WILLIAMS:** Or the sister's children nephews and nieces. All that ties in to it.

**Mrs BRAHAM:** What about the white doctor who did it?

**Mr WILLIAMS:** He would probably be accused for doing it.

**Ms COX:** There would be a big stink anyway.

**Mr RIOLI:** Amongst the families?

**Ms COX:** Yes.

**Mr WILLIAMS:** I mean, the person would be publicly accused of murdering him, in white man's language.

**Mr STIRLING:** Gus, Helen sort of said that it was just not in the minds of Aboriginal people, in the traditional way, to want to die in that way.

**Mr WILLIAMS:** She was correct in saying that. The word 'euthanasia' has never been around. We have not heard about it. It has only just been introduced.

**Mr POOLE:** There is no Aboriginal word for suicide either, is there?

**Mr WILLIAMS:** No.

**Mr POOLE:** Yet some Aboriginal people occasionally commit suicide for whatever reasons.

**Ms COX:** Yes but you only hear of them in gaol, when they are all locked up.

**Mr WILLIAMS:** When I think of all the people I have known in my life, in the sad times and good times, I do not think I ever heard of someone committing suicide.

**Mr POOLE:** I have not lived here that long, only since 1979, and I cannot really think of anything apart from the gaol situation.

**Mr WILLIAMS:** I am nearly 60 and I have been around my people all my life, since all Aboriginal people started getting close together. In the 1950s, tribes lived separately. But now with intermarriage and all that you know almost everything that is going on.

10

---

**Mr POOLE:** But there are lots of stories about a long time ago and most of them are probably rubbish, talking about how when families could not feed babies, they were in effect euthanised.

**Mr WILLIAMS:** Could be, you know. It could be that this occurred. A lot of things that we heard more publicly, you know. It is not a nice thing to talk about, being shot. But never euthanasia. Maybe this is not the time to talk about that. We are talking about a different thing.

**Mr POOLE:** Sure.

**Ms COX:** I feel that Aboriginal people know when they are going to die. My mother lived with me and she just woke up one morning and said: 'I am going to back to my own country to die'. She was dead in 6 months. So I feel Aboriginal people ...

**Mr POOLE:** Did she die through illness or just old age?

**Ms COX:** She died through an illness and she did not even know she had it. She had an operation in the Alice Springs Hospital for a bowel obstruction and she died with a blood clot. She knew she was ready to die so she come home. She was only a young woman.

**Mr POOLE:** I am presuming from what you say that she would not have said: 'Hurry up with the process'.

**Ms COX:** No. I am just saying that Aboriginal people have an insight into how long they have to go.

**Mr POOLE:** I think you would find that a lot of white people would do the same thing.

**Ms COX:** If they had an illness. But my mother did not have an illness.

**Mr POOLE:** Yes. You often hear stories about people who say, 'My time has come' for no logical reason. Six months later, they are dead.

**Ms BLENNER-HASSETT:** The other thing is that you think that most people with cancer die with pain. It is not true. Many people with cancers die comfortably. We have great drug controls for pain now. However, there are a few people who are in excruciating agony no matter what you give them. It seems to me that pain is the big issue for somebody wanting to actually speed things up. It is that unbearable pain day and night.

**Mr POOLE:** I think Marshall Perron has said that, in the context and the confines of the bill, it will probably only apply to 14 or 15 people a year in the Northern Territory. Others have said that that is not true and it will involve thousands of people.

**Ms BLENNER-HASSETT:** I do not think so.

11

---

**Mr POOLE:** Gus, there are a couple of places in the world that allow this to happen. It is legal in Oregon in the United States. However, a challenge in the Oregon Supreme Court has in effect stopped it. In Holland, whilst there is a tacit understanding between the public prosecutor and the medical profession which allows it in certain circumstances, it is still not really legal. They have just agreed not to prosecute the people involved. That is one of the big arguments because it effects about 25 000 people a year in Holland.

**Mr WILLIAMS:** That was my next question but you have ...

**Mr POOLE:** There it is not just for the people who say: 'Me please'. Relatives can say: 'Help my father, my brother, my sister or whatever'.

**Ms COX:** Can I ask a question? My daughter brought this up. I do not like to talk about it. She said that, if she had an accident and was in a coma and none of the machines worked, she would like to be put to sleep. I said that I would not give that permission. She said that she would go to a lawyer some time soon ...

**Mr POOLE:** Yes, that is called the living will. It can be done under the provisions of the Natural Death Act. You can sign a piece of paper saying that, if you were ever in an accident or were so ill that your life could only be sustained by a machine a life support system you would not want to be connected to such a machine.

**Ms COX:** Even as her mother, I would have no say over that?

**Mr POOLE:** That is part of what we are talking about, the right of the individual and the right of society.

**Ms BLENNER-HASSETT:** I thought next of kin actually had the right to overrule that. I saw a case in Victoria where a gentleman went through a huge rigmarole prior to getting very sick. He had signed a living will and he had been through the process with solicitors and independent witnesses. When it came to the crunch, his wife did not want it and the hospital had to stand by that. It is the same with organ donation. You can put things on your licence to say: 'I will give my kidneys or anything else'. But if your family or next of kin do not approve, they have the right to overrule what you have actually requested yourself.

**Mr POOLE:** I think that, in respect of the living will, you basically have to take court action to stop it. Then the court would decide.

**Ms BLENNER-HASSETT:** But I have seen a case involving a very severe quadriplegic in Victoria ...

**Mr POOLE:** The natural death legislation does vary from state to state.

**Ms BLENNER-HASSETT:** It was as if they knew that this quadriplegic wanted to go home on his life support system simply because he wanted to die. He did not want to be relying on this machine for the rest of his life. The hospital actually had him sectioned and confined to the hospital.

**Mr STIRLING:** Mr Chairman, if the bill is to become law, there would be an enormous obligation to have very comprehensive education programs in all Aboriginal communities. It may be that Aboriginal people simply decide: 'This is not for us. We do not like this'. But at least they will understand that the bill is there. They might want to have no part of it but at least there will not be fear, misunderstanding and anxiety.

**Mr POOLE:** That is one of the arguments that Marshall Perron has put forward. If people do not understand or are not particularly aware of their rights, it will not affect them. A person has to put up their hand and say: 'Please doctor, put me to sleep'. His argument is that the bill does not affect people who do not do that. Others say that that is not the point. They say that society should have the right not to allow people to do that. It is a bit like asking the extended family. While Gus Williams might want to put himself to sleep, the rest of the community might say that it is not right, and they would have the power to say no. That is probably the major issue whether it is the right of the individual person or the right of society.

**Mr WILLIAMS:** I think Mr Stirling is right. There needs to be education so that people in Aboriginal communities can understand it.

**Dr LIM:** As far as this community is concerned, I get the feeling that your response is: 'We do not know. We do not understand it and maybe we should wait a bit longer'. Is that what you are saying?

**Mr WILLIAMS:** No, we want to learn more about it. It is not the same thing ...

**Dr LIM:** Once it becomes law, it is law and that is it. It is going to affect all of us in the Northern Territory ...

**Mr WILLIAMS:** When do you expect him to make it law?

**Mr POOLE:** Maybe in May.

**Ms COX:** True? Is this going to go to a referendum?

**Dr LIM:** No. So that is the question.

**Mr WILLIAMS:** Gee, it is April now.

**Mr POOLE:** Yes, that is right.

**Mr WILLIAMS:** So it is going to become law in the parliament.

**Mr POOLE:** Well, you are making the assumption that it will pass.

**Mr BELL:** The numbers are not looking good at the moment.

---

**Ms COX:** I would like to know how we stand as Aboriginal people, where there are payback concerns or if it interferes with our dreaming and our cultural ways. I can tell you that I do not want to be paid back.

**Dr LIM:** I suppose I may be giving a fairly simplistic version, which is not really fair to you. I am trying to get it clear in my head because 25% of the Northern Territory population is Aboriginal. What I am hearing now is that there are a lot of concerns here at Hermannsburg. Is that the same with other Aboriginal communities?

**Ms COX:** I do not know. I am talking for myself.

**Dr LIM:** Sure.

**Mr RIOLI:** But do you think that is something that is part of the culture for Aboriginal people in this area?

**Ms COX:** I do not know. We have about 4 languages here.

**Mr WILLIAMS:** I think if it is in ...

**Mr RIOLI:** Is it something they would support or ...

**Mr WILLIAMS:** It would need to be translated and interpreted, in people's own languages. Otherwise they would not be happy with it; they would not feel comfortable.

**Mr POOLE:** Even if you really had the time and you went around to the community explaining all the things, even on the basis that it was only the individual who decided?

**Ms COX:** Can you say that again?

**Mr POOLE:** If there was more time, and if teams of people visited communities to discuss and explain the bill in language, and if people came to realise that the bill only affects individual people who are very sick and ask to be put out of their misery, do you think they would still vote against the bill?

**Ms COX:** I do not know but I would say so myself.

**Mr POOLE:** Is that because of the cultural aspects with respect to payback and the family not being part of the decision?

**Mr WILLIAMS:** I do not think it is fair if it becomes law in May. I do not think that the Chief Minister has given us a fair deal, you know.

**Ms COX:** Me either.

**Mr WILLIAMS:** The Chief Minister should give us another 6 months or so.

---

**Ms COX:** This is a big issue. To me it is like killing off our people.

**Mr WILLIAMS:** Yes, I think so.

**Mr POOLE:** He is not suggesting that anybody be killed off.

**Ms COX:** Yes, I know. But as an Aboriginal person, that is how I see it.

**Mr POOLE:** But he would say that it does not apply to you because you just said: 'It is not for me'.

**Mr WILLIAMS:** If Aboriginal people have to say yes or no, I think we have to be educated more. It comes to the same thing at election time. You want our vote? You either get it or not.

**Mr POOLE:** Sure.

**Mr WILLIAMS:** It took a long time to be educated on how to cast a vote.

**Mr POOLE:** Yes.

**Mr WILLIAMS:** What are we going to say about this bill?

**Ms COX:** Yes.

**Mr POOLE:** Well, that is why I ...

**Mr WILLIAMS:** Maybe a referendum like somebody suggested. We are ready to cast our vote on that.

**Mr POOLE:** Gus, some polling has been done on this and the indication is that 70% of the population probably supports the bill. Even if 25% of the population voted against the bill, it would still become law. I say that because Marshall deliberately brought it in as a private member's bill. I am sure that he would have realised that it would not have been possible to bring it in as a CLP bill because half of the CLP say no and half say yes.

**Mrs BRAHAM:** If this bill does pass, just remember that it is not mandatory for everyone to be euthanised. You still have the right to say no. If it is passed, it is for those people who want it. From what I hear, Aboriginal people are saying: 'This does not fit with our culture at all'. Aboriginal people probably do not want to have anything to do with it and it is their right to say no.

**Mr POOLE:** It is an unusual law because most laws are passed for the benefit of the community. Although they only affect a minority, laws about drunken driving and speeding apply to everybody. However, if this becomes law, it will only apply to those who want it applied to them. That is one of Marshall's arguments. Other people are saying that it should be a matter for society and not for the individual.

I think that, in all Australian states, the former crime of suicide is no longer a crime. It is not illegal to commit suicide. It is illegal to attempt suicide and that law really was passed to stop people jumping off the top of buildings and landing on people walking underneath. However, it is not illegal to commit suicide. The Territory is one of the few states where that has not been removed.

**Mr BELL:** So it is not in the Queensland Criminal Code?

**Mr POOLE:** No.

**Mr STIRLING:** It remains illegal to assist.

**Mr POOLE:** Yes.

**Mr STIRLING:** That is the problem.

**Mr WILLIAMS speaks in language.**

**Mr WILLIAMS:** The bill is sort of going through or whatever in May. I have asked that they give us another few months, 6 months or whatever. It is only for individuals..

**Mr POOLE:** It is probably not correct to say that it is going through in May, Gus. It is going to be discussed and, although I do not really know, I would offer the observation that I suspect that a lot of people in the parliament will not be voting for the bill. That is one of the reasons why we have a pretty mixed group here. There are probably some people here who support it and others ...

**Mr WILLIAMS:** I understand that, yes.

**Mr POOLE:** ... who are against it or violently opposed to it.

**Mrs BRAHAM:** The Aboriginal group who appeared before us in Darwin said that, if an Aboriginal person was dying, anything like this should be discussed with an interpreter present so that no decision could be made unless they were thoroughly informed and knew exactly what was going on. They said we should have the bill in language and should at all times ensure that an interpreter was present so that the person knew what was being asked of them, rather than just having a doctor ask without the person really understanding what was going on.

**Mr WILLIAMS:** That is getting back to education, isn't it?

**Mr POOLE:** Gus, one of the worrying aspects of the bill, it that there is already a fair amount of talk among elderly people in the white community that this might be used by governments as an excuse to avoid spending the money to look after them. We would certainly want to make sure that people did understand it because otherwise we might be in a situation where Aboriginal people were scared to go to hospital because they do not understand the possibility.

---

**Ms BLENNER-HASSETT:** That is what has to be made clear. If you do not want a bar of this, it does not affect you. It is simply for a few cases. Even though it is an individual signatory's right, I doubt that there would ever be a situation in which there was no family discussion about it. Most families caring for a sick person know how the person is feeling. In the few cases in which I have been asked to do something about it, I have been asked by the family.

**Mr POOLE:** To be clear about this bill, it has no provision that makes it mandatory for the patient to discuss the matter with his family or for the doctor to discuss it with the family. The requirement is for the patient to request the doctor. The doctor must firstly agree that the illness is terminal, secondly find another doctor who agrees with the diagnosis and thirdly talk to the patient to make sure that it is what the patient wants. There is no provision in the bill that ensures that the family has to be involved.

**Ms BLENNER-HASSETT:** I know that is the case as far as the bill goes. But in terms of the human face of death and dying, there would be very few cases, especially in Aboriginal culture, in which the family would not be involved in this discussion.

**Mr POOLE:** In theory, of course, someone with terminal cancer might come in to the Alice Springs Hospital from the Western Desert area. There might be no close relation in town. The person's pain and suffering might be such that they say: 'I understand that you can put me out of my misery. I am going to be dead in 6 months at any rate. Please fix it'.

**Ms BLENNER-HASSETT:** No discussion with next of kin.

**Mr POOLE:** You would not have a discussion with next of kin.

**Ms BLENNER-HASSETT:** I have a problem with that.

**Mr POOLE:** That is the sort of thing we are trying to find out.

**Mr WILLIAMS:** Yes, there is a problem.

**Mr STIRLING:** It is an unlikely scenario.

**Mr POOLE:** I know that it is unlikely but I believe that it is a grey area of the bill.

**Mr STIRLING:** But from what I hear, it seems unlikely that an Aboriginal person would say: 'I want to die'.

**Mr POOLE:** Perhaps it depends on the circumstances. They may have been brought into Alice Springs and then flown down to Adelaide and back, and they may not have any family member with them. It does happen, although not very often. I think it is a grey area. It is something we can discuss.

---

**Dr LIM:** In most instances, whether a person was black, white or Chinese, they would say: 'Look, I think I do not want to live any more. I am in too much pain. But let me talk to my relatives first'. I have never encountered a patient making that sort of request in a vacuum without consultation with their loved ones. I suppose, however, that it is possible.

**Mr POOLE:** I just believe that people should understand that there are worst case scenarios.

**Dr LIM:** You have heard us talk about this here and perhaps you have a better understanding than somebody else. I do not wish this upon you at all. However, if you get really sick, would you be too scared to go to a hospital for treatment? If this bill was passed, would it make you scared to go to hospital for treatment? Do you think the doctors might not help you or whatever?

**Mr WILLIAMS:** Most of us have already had some sort of treatment. I do not think it would stop a person going to hospital for something other than euthanasia. I do not think that anybody is frightened of hospital any more.

**Mr POOLE:** In summary, I think you have been telling us that your community would generally not be supportive of the bill without a lot more discussion.

**Mr WILLIAMS:** It would need to be interpreted to us in our language.

**Mr POOLE:** All right. Does anybody else want to ask us anything or say anything?

**Mr WILLIAMS:** No.

**Mr POOLE:** Is everybody happy over here? Okay, I think we'll wind it up there, Gus.

**Mr WILLIAMS:** Yes.

**Mr POOLE:** I would like to thank you and your friends and relatives for appearing and talking to us today. Thank you very much.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 15.05 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Tricia Smith

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

1

---

**Mr POOLE:** In commencing this hearing of the Select Committee on Euthanasia on Monday 3 April 1995, I welcome Ms Tricia Smith, who is appearing as a witness to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that the committee has authorised that for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case?

**Ms SMITH:** No, I am quite happy for this to be public.

**Mr POOLE:** Thank you. For the Hansard record, could I ask you to state your full name and the capacity in which you appear today.

**Ms SMITH:** My name is Patricia Anne Smith, more commonly known as Tricia. I appear today as an educator for 25 years at primary, secondary and university level, as one who focused on death education in studying for the degree of Master of Educational Studies, as a person who designed death education curriculum for primary schools, and as a care giver trained by the Victorian AIDS Council.

**Mr POOLE:** Thank you. So far in public hearings we have allowed people to start by speaking to their submissions. You obviously do not have to read out what you have supplied us with unless you want to ...

**Ms SMITH:** No. You would be here for 3 weeks.

**Mr POOLE:** If you would like to speak to your submission first, we will then go into a general question and answer session. From a timetable point of view, we have allowed you 45 minutes. We are running about 5 minutes late so we will go till 3.50 unless you finish beforehand. Over to you.

**Ms SMITH:** The introduction to my submission mentions my interest in this particular legislation. I would like to stress from the outset that I do not think it is a political issue. I firmly believe that it is a human rights issue and I will be presenting from that perspective.

The fact that it is not a political issue is quite evident today with the politicians who are present and the fact that I am strongly supporting Marshall Perron on legislation when I am a paid member of the Labor Party. I make that quite clear from the beginning.

I believe that death is an integral part of and a natural component of life. Life is all about decision making processes and choices. Therefore, if death is viewed as a natural part of life, people have the basic human right to make a choice a life choice which includes death.

---

I have prepared a diagram in the form of a wheel. I did not get my Masters degree for artistic skills, so forgive me for the basic presentation. What I have attempted to portray through this visual representation is the whole death picture. I believe that voluntary euthanasia is only a micrographical part of the whole macrographical death picture.

There is a social taboo on the subject of death, and the whole subject is very mystified. That has come through quite strongly in surveys which I have conducted here in Alice Springs. You have copies of the surveys and I will not go into the percentages now.

Within this wheel or this taboo area, I have marked voluntary euthanasia as a small part. If we look at the big death picture in western society, we find that we have created an evasive language. Most people are very reluctant to say that somebody has died or somebody is dying.

The terminology that has been created includes terms such as: 'passed away', 'departed', 'gone', or 'asleep'. These epitomise the social stigma or taboo that we have created. Until several years ago, suicide was an illegal practice. People who chose this path were refused the right to be buried by the Catholic Church I cannot speak for other churches and also the right to be buried in cemeteries. I think we have come a long way since then in terms of recognising this basic human right. I have included that as part of the taboo area although fortunately attitudes towards suicide have become more humane.

I have mentioned institutionalism in this death wheel. That is because I believe that the move has been away from the natural process and dying in the home and death being a natural part of life. It is being shoved into hospitals. The process has been institutionalised. In many instances, the power, control and decision-making has been taken away from the patient and is in the hands of the families, the doctors or the paramedics. That is unfortunate but it is a reality. We have institutionalised what was once a natural event in the home. People grew up seeing it as part of life, knowing that nana, mum or little brother or sister was dying. Now we see institutionalised death.

Within the wheel I also mention the lack of recognition of the important grieving process. That is what prompted me to implement death education in the school where I was principal and teacher. During 1988, the school suffered a death experience once every 2 months. The parents and the kids were in a constant state of grief and mourning. At that time, so that I could cater for the needs of the community, I undertook to travel to Melbourne to undertake training in death education, emotional awareness, grief and loss.

The school program was successfully introduced. I think it was the only such school in Victoria. I would love to know how many schools in the nation have death education programs. They are so important because everyone faces some form of loss.

This ties in with institutionalism. When my mother died in 1987, I had been her principal care giver. I was a teaching principal at the school I just mentioned. I was allowed to take just 3 days off for my mother's funeral. I ask about that, particularly when we look at

Maurice's culture, where they have 'sorry business' that is not determined by temporal boundaries. People are allowed to go through the grieving process and cope with grief and loss. Just 3 days! If that is not an institutionalised structure and a rejection of the whole process, then I do not know what is. You are expected to return to the classroom or to work in whatever profession and carry on as though the loss has not occurred.

The wheel has been an attempt to illustrate that the opposition to and rejection of voluntary euthanasia is a typical response to all the other areas that are involved in the whole death picture. I have finished speaking to that.

I now turn to cultural perspectives and the second hand-out that you have. It is the one with the heading Western Society and NonWestern Society. In my research for my Masters degree, I examined about 60 books on the subject and various cultures. I found that western society overall is death denying and death defying. The evidence is that nonwestern societies are more accepting of death.

The marks on those lines are not scribbleouts. They are meant to be spiral representations of processes that are occurring. This line represents the metaphysical or spiritual world. The horizontal line underneath represents the physical world. I believe that, in western society, the spiritual or metaphysical world is up there somewhere. It is totally removed from our very humanness and the physical world that we live in every day.

When we look at nonwestern societies, which are more death accepting, the dimensions are interwoven. The spiritual world is part of the physical world. I believe that this is where dilemmas arise in western society. When one is facing death, people discover that the physical and spiritual world has met with the physical world. That is where all the confusion takes place. I believe that, through education, we have to get to a stage in society where these two are married together and where they are not divorced from each other.

Looking at the death process and the rights of the individual, I believe the legislation about empowerment of people and selfdetermination. I believe that people have the right to determine their own lives. I believe they have the right to be empowered throughout the death process, to maintain that power and control over what is happening to them.

The next hand-out has my little primary school creatures on the right hand side. I came up with this because I asked: 'How can 20% dominate or try to influence 80% of the population? Why and how can this be?' When I thought about it in light of institutionalism, which I studied mainly in relation to racism, I realised that a lot of the opposition is coming from minority groups which have very strong institutional power bases such as the churches, the medical profession and the health system. The minority are represented by the double strength of an institutional structure and the values and ideals that have been embedded in those institutions.

When you look at a society in which institutions are pitted against individuals, even where the individuals comprise an 80% majority, it is clear that the individuals lack the double

---

strength of the institutional power base. I think that, as politicians, you should be very aware of this in order to ensure that any decisions made in parliament should reflect the views of all people within the population, and not just those who are privileged because of institutional power.

I would like to quote from something that I read with great interest. It refers to section 116 of the Commonwealth Constitution, which clearly states that the Commonwealth 'shall not make any law for establishing any religion or for imposing any religious observance or for prohibiting the free exercise of any religion'.

I think the current legislation does exactly that. It excludes people on the basis of their religious belief systems. I do not belong to any established religion but I believe that I am a very spiritual person. I believe that my belief system, through which I live my daytoday life, is just as valid and important as established belief systems. I believe that has to be recognised. People who do not share the same belief system or plausibility structure, which derives mainly from the Christian viewpoint and has historically influenced much of our legislation, should not be denied the rights that others have.

I ask members of the select committee to really think about that one in light of the Commonwealth Constitution.

**Mrs BRAHAM:** Trish, can I just ask you to clarify that? You quoted section 116 of the Constitution, which basically says that the Commonwealth shall not impose any religious observance. Basically you are arguing that those who argue against this bill on religious grounds should not be imposing their will upon the majority. You are basically saying that, if the law is not passed, it is imposing their religious observance.

**Ms SMITH:** It is certainly doing that. I am saying that. It is dual-pronged, Lorraine, in so far as the current legislation ...

**Mrs BRAHAM:** What do you call the current legislation?

**Ms SMITH:** I mean that the lack of voluntary euthanasia legislation is only catering for people who do not choose voluntary euthanasia. It is only catering for those who believe in the existing parliamentary value and belief system. It is imposing values and beliefs upon others, unless it is legislated to be allinclusive and allencompassing. Furthermore, current practices and legislation are prohibiting the free exercise of any religion.

**Mrs BRAHAM:** That could be argued in reverse though, could it not? It could be argued that people who are against the bill on religious grounds are exercising their religious belief also.

**Ms SMITH:** Yes, but I do not believe that their religious beliefs are being imposed upon. They are not forced to make the choice of voluntary euthanasia. The legislation allows everyone to have a choice. It does not force people to choose it when it conflicts with their religious beliefs. They still have the right not to choose it. However, the present situation denies and excludes ...

---

**Mrs BRAHAM**: The rest.

**Ms SMITH:** Yes, and I believe it has to be inclusive legislation.

I do not believe that voluntary euthanasia legislation is radical legislation. I believe that it is long overdue. I know for a fact that euthanasia is occurring in all sorts of ways. The current situation places extra burdens and responsibilities on family members, care givers and those who are near and dear, particularly when compassion and respect for the right of the individual wins through and family members take the law into their own hands to fulfil the choices of a dying person.

This has been going on for a long time in all sorts of fashions, and I do not see the legislation as radical or even progressive. I see it as keeping up with social needs and rapid social changes. These changes have occurred throughout the technological age. In the case of professional practices, legislation too often becomes inappropriate and outlives its temporal boundaries.

What was considered appropriate at a historical point in time is not necessarily relevant at another point in time. I would like to stress that. I would liken it to what occurred in 1975, when I was chosen as District Language Arts Consultant under the Commonwealth Whitlam government to implement the language curriculum statement for about 30 schools in the Warrnambool District. Teachers were shuddering because it was the first time that a prescribed course of study was not considered appropriate. It was the first time that, having been equipped with a statement, the onus was on teachers to design their curriculum in accord with client or student needs.

It was a radical change at that point in time. It took away teachers' security. Previously, they had been spoonfed and told what to do. The change was long overdue because prescribed courses of study were not appropriate to the social and educational needs of children and their holistic development. I liken this legislation to that period of time. As I said before, it is long overdue; it addresses current social and human rights needs and client needs.

A district inspector said to me at that particular time: 'Pat, in education you take 4 steps forward and 10 steps back'. I ran into him 3 years ago in the streets of Warrnambool and he stopped me and said: 'Pat, I remember that advice I gave you but I am so pleased you took the initiative. Otherwise we would still be marking time today and education would not have moved forward as it did as a result of your input'.

That is the reality. We have to be prepared to do that sort of thing. It means change and it also means moving away from the traditional way of thinking. But it has to be done.

Talking about appropriate death practices raises the issue of palliative care. I might add that, through the Victorian AIDS Council, I believe that I have been on teams providing the best palliative care that you could ever see in this country. The council's model for 24 hour palliative care in the home has been adopted overseas.

Palliative care is a crucial issue but it is quite separate and distinct from the voluntary euthanasia issue. I am concerned that people are merging the two together.

When we look at palliative care and when we look at death practices, I believe medical practitioners have the responsibility within their profession to deliver best practice in service delivery. Best practice in service delivery is not just cut and dried carte blanche one recipe for everyone.

I believe best practice in service delivery involves best meeting the needs of the patient or client and fulfilling their life choices. It means allowing them to live and I say 'live' not exist in a manner which they have determined and in a manner that is fitting in terms of the lifestyle to which they are accustomed.

As you will see at the end of this, I have a personal concern about the legislation. In a lawyer's office in Warrnambool, my will and a letter are kept. One of my greatest concerns in life is to suffer from dementia and be locked away in a home without my mental faculties. I am so strong on that that I have left a note saying that I would wish to die if ever that happened. I believe that is my choice, and my concern with Mr Perron's legislation is that it is not inclusive enough.

I wrote that letter and that will at the age of 40 in sound mind. I would like to see, somewhere in the legislation, an acceptance of human rights not only in the physical sense of suffering, but also in respect of the choice that I would like to make.

**Mrs BRAHAM:** So you are saying that people should be able to stipulate what they want well in advance. With the bill as it now stands, a person's choice is virtually eliminated if they go into dementia.

**Ms SMITH:** I can understand that if a person has gone into dementia, Lorraine. I realise that they cannot make an informed decision or choice. That is why I have prepared this now. Hopefully, I can choose a legal practice and not an illicit practice at that time in my life, if I am unfortunate enough to be inflicted with such a form of suffering.

In the event of me not being able to determine that myself, I have named 3 people whom I trust explicitly, to make that decision for me. If there is any way the select committee can make a recommendation to cover people of sound minds who have made that sort of written request, I would certainly appreciate it greatly.

I mentioned that best practice in service delivery should be based on client needs and not determined by external forces. It should be determined by the patient himself or herself. As I said, if life is about selfdetermination and empowerment of people, so is death.

Ethical conflicts will arise, perhaps because of a shift in the methodology of medical practice. However, ethical conflicts have occurred in the past, as I illustrated with my teaching example. They have also occurred within the Catholic Church. I remember when an encyclical

promoted the wearing of lay people's attire. Some of the nuns absolutely freaked. I have some personal friends who are Good Samaritan nuns. The shock and horror which accompanied the change was intense, particularly for some of the older nuns. It was, however, an overdue change. It was necessary for those religious orders to be seen as part of ordinary, everyday society rather than as people running around in strange garbs.

Whilst there will be concerns, I believe they are part of the transitional process. They should not prevent the law from keeping up with social or cultural needs. Actually, I spoke to a friend in Melbourne on Saturday. She is a Good Samaritan sister. She was talking about her mother, who has reached a stage where she is crying every night and will not sleep unless my friend, Sister Helen, or one of her brothers or sisters is in the room with her. I was talking about this legislation. I thought that it would be interesting to hear Helen's view as a Good Samaritan nun. She said that she fully endorses the legislation, provided the decision is made by the person in the situation and not by external bodies. I thought that was rather interesting, coming from her.

In all fairness, even though I am a very strong advocate of the legislation apart from the concern I raised, I believe that the select committee and the democratic process should look at both sides of the issue. Some concerns have been raised to me during the process of circulating my questionnaires.

One concern is that people's lives will be terminated against their wishes and that this will be common practice. That seems to be a number one concern. On the sheet which I gave to the committee, I mention the need to overcome such concerns. I also mention that malpractice is occurring now. There are no two ways about that. It is not the result of the legislation because it is already happening. I can see the legislation allowing for control of current practices which is now nonexistent. There is no control at the moment. I believe that such control would erase the fears of many people.

**Mr POOLE:** Trish, you have just said that it is already happening in our society.

**Ms SMITH:** Yes, it is.

**Mr POOLE:** Would you put the same argument in respect of the use of heroin or some of the liquor laws of the land. Would you say that, if people are breaking the law, we should change the law so that their behaviour becomes acceptable?

**Ms SMITH:** I see the use of heroin or drugs as a form of escapism, or something which some people need at a given point in time. Perhaps people do not choose to use it; perhaps they become addicted or whatever. However, I do not see that as a basic human rights issue.

**Mr POOLE:** Heroin is probably a bad example. What about cannabis? Many people in our society believe that smoking cannabis is no worse than having a drink or smoking a cigarette.

**Ms SMITH:** That is right.

**Mr POOLE:** In some areas around the country, it has been decriminalised to an extent ...

**Ms SMITH:** They have, yes.

**Mr POOLE:** Are you saying that that is the argument for what we should be doing with this euthanasia bill.

**Ms SMITH:** As far as euthanasia goes, death affects everyone's life. We are all born and we all die. If people choose to use cannabis, it does not affect everyone's life. It is up to an individual to choose. It will probably be made legal one day. When it is decriminalised, better controls can be implemented.

**Mr POOLE:** But you would not apply a similar argument to more serious issues, such as the crime of murder.

**Ms SMITH:** You certainly would not condone people who ...

**Mr POOLE:** So it really depends on what you see as the seriousness of the law.

**Ms SMITH:** You are referring to practices which are considered to be antisocial, whereas I do not believe that death is an antisocial practice.

**Mr POOLE:** No, but sections of our society would suggest that it is fairly antisocial for doctors to kill people.

**Ms SMITH:** I do not see it as doctors killing people. I think we have to be very careful with our terminology.

**Mr POOLE:** I am not saying that I do.

**Ms SMITH:** No. I see it as doctors allowing people to make a choice that is their right. It is doctors accepting and recognising the individual way in which a person chooses to die. I mentioned best practice before. I worked as a night manager in a home for old folk and I saw some heartbreaking situations. One elderly woman called Hannah cried day and night. It was an incredible effort to get her out of bed, to take her down to try and get some breakfast into her. She just wanted to die. For months and months and months, that woman cried and wanted to die. Eventually she did. It is not a question of doctors killing people. It is doctors respecting people's right to make choices and allowing them to have power and control over their own life process.

**Mrs BRAHAM:** Would you tie this bill in with social justice principles?

**Ms SMITH:** Definitely.

**Mrs BRAHAM:** How do you tie it in?

**Ms SMITH:** As I said, it is a human rights issue. It certainly falls into the social justice category. At this time in Australia, some people are given rights of privilege in respect of death whilst others are denied those rights because voluntary euthanasia legislation is not in place. If we are honest about social justice, one segment of society should not be denied rights which are available to other segments.

**Mr STIRLING:** Patricia, do you intend to deal with your survey before you finish your presentation?

**Ms SMITH:** I did not intend to, because I think all committee members have a copy. I prepared the survey so that it would relate to the philosophy of the legislation. I was looking at the attitudes of people from the human rights and social science perspectives. The survey sample consisted of only 100 people but was very inclusive in terms of those who participated. They included: adult males, adult females, Aboriginal adults, nonAboriginal adults, adults from different religious denominations, age groups from about 19 to 70, and people from diverse socioeconomic backgrounds. 100% of the participants believed in basic human rights.

**Mr STIRLING:** I am interested in that question. I guess the finding is no surprise but where did it take you in terms of ...

**Ms SMITH:** In terms of the legislation? Before I handed the questionnaire to people, I asked them to answer it in relation to the Rights of the Terminally Ill Bill. I told them that I believed it was a basic human rights issue. Some respondents had read the bill and some had not but they knew that the questions related to the bill. Responses to question 8 were very direct. The question asked about respecting and accepting the dying wishes and choices of terminally ill people and the imposition of values.

**Mr STIRLING:** In my view, you missed the most fundamental question. You began your paper by saying that western society evades issues of death and dying and has created euphemisms for it. However, out of 10 questions there is not one that says: 'Do you support the right of a terminally ill person to make a decision to seek assistance to die?'

**Ms SMITH:** As you can see from the document itself, it was done in conjunction with the philosophical issues. I deliberately did that because I wanted to gauge whether public attitudes respect and accept the dying wishes of terminally ill people. If the dying wish of terminally ill people is to have assisted suicide, the responses of 97 of survey participants are relevant. They indicated that they would respect the dying wishes and choices of terminally ill people. These would logically include assisted death.

**Mr STIRLING:** It would not be as clear to me as if the question itself was there with 97% beside it.

**Ms SMITH:** But I did not want to single out just one aspect. There are choices. The crux of is respect for the right of choice of the terminally ill person, no matter what that choice might be.

**Mr POOLE:** There does seem to be a difference in what Syd is saying. I would expect that, if I asked people whether they believed in human rights, at least 95% and probably 100% would reply almost automatically in the affirmative. They would say: 'Yes, we do'. However, it would not necessarily be the case that those people would see ending one's own life as a human right. Do you see what I mean?

**Ms SMITH:** I know what you are saying but when I handed out the questionnaire and discussed it, people understood that it related to the rights of the terminally ill.

**Mr POOLE:** I am saying, while people might overwhelmingly say yes to a question asking whether they believe in human rights, a question asking them whether they believe that people should have the right to invoke voluntary euthanasia might attract a very different response.

**Ms SMITH:** I think voluntary euthanasia definitely comes into question 5: 'Do you believe that people should suffer unnecessarily when dying from cancer and other painful terminal diseases?'

**Mr POOLE:** Yes, but I assure you that some people who have appeared before the committee would say: 'No, I do not believe it but it is a fact of life and I do not believe they should have the right to kill themselves'. All I am saying is that we are used to surveys as no doubt you are from an academic perspective. I tend to believe that surveys are simply a matter of interpretation.

**Ms SMITH:** Yes, definitely.

**Mr POOLE:** If I do a survey on which is the best party to govern in the Northern Territory and give the results to an ALP man and a CLP man, their interpretations will be very different.

**Ms SMITH:** Yes. I was talking about individual interpretation in response to the answers.

**Mr STIRLING:** Patricia, I am not surprised that the answer to question 5 is 95% negative. I am surprised that it is not 100%.

**Ms SMITH:** Yes, I know.

**Mr STIRLING:** I would like to look at question 8: 'Do you believe people should be making excessive and unnecessary money at the expense of dying patients?' It is a pretty loaded question. Again, I am surprised that 100% did not reply in the negative. What evidence do you bring to that question?

**Mr POOLE:** The one respondent was a doctor.

**Ms SMITH:** When studying health and human relations, I became aware that we have created a death industry. As frightening or alarming as this institutionalised death process might be, it is a reality.

**Dr LIM:** What do you base that judgment on? What evidence do you have that people are making excessive and unnecessary money out of dying patients?

**Ms SMITH:** Where life is prolonged against the wishes of some patients, you have paramedics, the engineers of life support machines, hospitals, florists and funeral parlours. They have established institutionalised businesses. That is the reality.

What happened to the days when people were buried in basic caskets? It was horrifying when my mother died. You are given these brochures; it is like buying a house. You start at a basic $1000 or $2000 coffin and go up to something worth $80 000. Those are the realities. We have institutionalised it. We have removed it from its natural environment and its natural purpose in life. We have allowed this to happen and that is what I mean by the death industry.

**Mr POOLE:** But this bill will not make any difference to that, will it?

**Ms SMITH:** We can always create death education programs for schools and create an awareness that will help to address these things. In a sense, it will help in terms of that small minority who may choose voluntary euthanasia.

**Mr POOLE:** But they will still get involved in the $1000 coffin or the $20 000 coffin.

**Ms SMITH:** No, not if they leave wills specifying that their caskets by made by the unemployed or whatever. My point is that it is definitely an industry.

I think time is running out. I would like to leave you with some of the other concerns that were raised. One relates to people who may feel depressed and may express a wish to die on one day but change their minds the following day. To overcome that concern, a patient must firmly establish that this is his or her chosen path. Systematic mechanisms must be devised within the legislation to ensure the sincerity of the request so that it is not done willynilly. It has to be definitely the choice of the person concerned.

I think the Constitution makes reference to the human being as a religious or spiritual being. Doctors have been trained to save or prolong life, not terminate it. That was another concern. I have said here that doctors are being trained to provide best medical practice. As in any profession, best practice should be determined by client needs. Service delivery undergoes constant change according to the needs of clients.

People are saying that there is a need to improve palliative care. I am not against the improvement of palliative care; I fully support it. My response, however, is that palliative care is a separate issue and quite distinct from voluntary euthanasia.

I will read a brief poem which I wrote and published in a book last year. Actually, Lorraine was at the book launch. When I first went to work and live with Aboriginal people, I had to face issues that are not dissimilar to those which politicians now face in the context of this legislation. I had to deal with things that were outside my frame of reference. These people had a belief system and a value system that were totally different from mine. I thought: if I am to be of any benefit to this community and to the holistic development of these kids, I must understand where they are coming from. I must cater for them. I cannot just act according to my own frame of reference and the value and belief system in which I grew up.

Whilst it is difficult, I believe that it is essential. The politicians must do what I did. On an issue such as this, they must be able to shed the value and belief systems which are part and parcel of them. They must be able to develop the capacity to distance themselves from that, to take a view from afar, to look at the big picture and to redefine the reality of situations which may be outside their own culturally determined frame of reference.

Only in this way can interpretation of social worlds be realistically determined, can blueprints be developed for pictorial inclusiveness and can the ideals of democracy reach meaningful fruition. I will just finish with this poem that I wrote on death being an integral part of life.

Being no longer death defying nor death denying.
The mystique is beautiful if a society is prepared to accept death as an integral part of life.
Why do human beings shudder at the mention of the word death?
Why do they pretend that the process is not taking place when the dying so desperately wish to share this life's experience?
Life is death.
Along the way we grieve our losses, a healthy human sign.
Mourning is part of the healing process as natural as the ebbing tide.
Let's take stock of our existence, the humans that we are.
Accept the pain and suffering as essential parts of life.
None of us were meant to be supernatural beings, yet we adopt all mechanisms to nurture false pretence.
Let us examine our humanness and open the door to death so that future generations can recognise and welcome this certain visitor.

Now, death accepting, we can life to explore all human aspects.
Fear, replaced by fearlessness, the unknown now the known.

**Mr POOLE:** Thank you. One could reply:

Yea, though I walk through the valley of the shadow of death, I will fear no evil.

**Ms SMITH:** That is right.

**Mr POOLE:** Thank you very much.

---

**Ms SMITH:** Thank you for your time. I did put a cutting in with the other material. When I was in Melbourne last week I was clipping newspaper items concerning the 7 doctors who challenged the government to either implement current practice or change the legislation.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 16.05 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative: Aids Council of Central Australia

Mr Peter Cram, Coordinator

Mr Douglas Vandermoran, Men's Educator

Ms Virginia Quinn, HIV Support Worker

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

---

**Mr POOLE:** In commencing this hearing of the Select Committee on Euthanasia, I welcome the following witnesses on behalf of the AIDS Council of Central Australia: Mr Peter Cram, Coordinator; Mr Douglas Vandermoran, Men's Educator; and Ms Virginia Quinn, HIV Support Worker.

May I remind you that, other than in exceptional circumstances, witnesses are not required to take an oath or an affirmation. However, I must remind you that any information you give to this committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the publication or disclosure of the material placed before the committee by witnesses does not apply. Witnesses, however, do have the right to request that their evidence or part of their evidence be taken in camera, and/or remain confidential. Please advise us now if that is the case.

**Mr CRAM:** No; what we are going to present here is public.

**Mr POOLE:** Fine. Everything will be recorded for the Hansard record and transcripts of what is said here today will be made available. I would ask you please to state your full names and the capacities in which you appear today.

**Mr CRAM:** My name is Peter Cram; I am the Coordinator of the AIDS Council of Central Australia.

**Mr VANDERMORAN:** I am Douglas Vandermoran; I am the Men's Educator at the

AIDS Council of Central Australia.

**Ms QUINN:** My name is Virginia Quinn; I am the HIV Support Worker with the AIDS Council of Central Australia.

**Mr POOLE:** What we have been doing so far is to allow people to say what they wish to say to the committee, after which we move into a question and answer session. We have allowed 45 minutes so we would like you to try and limit your remarks to about half an hour. Although we may occasionally interrupt to ask questions, we will try to give you the opportunity to say what you want to say first up.

**Mr CRAM:** Good afternoon. At this point in time, we have not prepared a written submission. We decided that we would first make a verbal submission through this process.

As we are from the AIDS Council, obviously what we have to say applies to people who are HIV positive. However, we believe that it also applies to other people with terminal illnesses.

Our views on the euthanasia bill derive from a harm minimisation philosophy which is also being used in relation to intravenous drug use and other policy formulation, especially in the area of HIV. From that viewpoint, as we see it, euthanasia does occur already. It is happening now in a number of places and in a number of places it is not working well.

---

As we see it, one of the advantages of this legislation is that it would make the process both legal and, relatively speaking, physically safe for the patient, family members and the medical practitioners who are involved in it. It would also stipulate who can do what and how, as opposed to the current situation where things are very much up in the air and in which those who choose to selfdeliver do so by whatever means they can find and whatever methods they can find out about.

We also feel that this legislation provides a practical means to the human right of having control over one's life, that right involving both the quality and the quantity of life. This legislation will also make it possible for grief counselling of relatives prior to death and may eliminate the relatives' usual response to suicide. It basically allows for the person's death to be planned, prepared for and organised, both for the person who is dying and for family members and friends.

It also allows for the financial support of the family, which is lost if the person formally commits suicide. This is especially important for HIV positive people in relation to life insurance and superannuation policies where, if a person is officially declared to have committed suicide, the policy benefits do not flow to the family. This bill would at least ensure that such families are financially supported.

We see that it is possible for this process to actually increase the amount of time between when a person makes the decision to selfdeliver, and when they take that action. This may allow enough time for them to change their mind, for their medical status to change, or for some other factor to play a part.

We feel that it is important for people in our society to have a choice. This euthanasia bill would be part of the choice. The choice would only be both real and effective if this euthanasia bill and a palliative care unit were both functioning in this region.

A palliative care unit on its own would not necessarily be effective. Quite often, it is very hard to prescribe opiate drugs for pain relief of intravenous drug users. There are also many people who would not find palliative care appropriate. Without the legislation, they would not have a choice. It would be palliative care or nothing. Similarly, if this legislation was in place without provision for palliative care, there would also be no choice. There would only be a single option.

In terms of the legislation itself, we do have some concern that it fails to take into account the possible safe and responsible use of advance directives, which have been found to be useful in other states especially in relation to people with HIV?

**Mr POOLE:** What do you mean by advance directives?

**Mr CRAM:** An advance directive is where someone writes down their wishes on a piece of paper with witnesses.

**Mr POOLE:** Leaving a will, sorry.

---

**Mr CRAM:** Different jargon. That more or less sums up our views initially.

**Dr LIM:** I would like to ask about intravenous narcotic users who may not be able to receive high doses of any form of analgesia. I question that. Suppose somebody is using many milligrams of heroin intravenously several times a day. Would it not be possible to provide morphine in doses sufficiently high to relieve their pain?

**Mr CRAM:** I made that observation on the basis of my own experience. It was not based on a medical viewpoint. It was based on the experience of having a number of people say that, because they were intravenous drug users, doctors or medical staff refused to give them opiate analgesics.

**Dr LIM**: Because?

**Mr CRAM:** In one particular incident, although the person was terminally ill, there was a concern that the person would become addicted again.

**Dr LIM:** That is not palliative care. You are talking about an uninformed medical practitioner making a value judgment about the use of narcotics.

**Mr CRAM:** Absolutely, and it is easy to go around that one in that case.

**Dr LIM:** We need to talk about palliative care in the true sense of the word;. If I give somebody enough morphine, it could do anything.

**Mr CRAM:** Yes, there are a number of points to make about that. I agree that it would do anything. The first thing it would do would be to take away that particular person's ability to go through the grieving process properly, to say goodbye to their relatives properly and so on. It would give that person the option of palliative care if they so chose it. Without this legislation, that would be the only option such people would have. They could either do that or, if they chose to selfdeliver, they would have to find some other illegal and possibly unsuccessful means.

I think palliative care is a great idea and, from my viewpoint, a very necessary idea. It is one option that would be good for our society to have.

**Mr STIRLING:** Peter, this a difficult area in the whole debate but I have asked this question of many of the groups who have appeared before the committee. Would you have any idea of the likely numbers of people in a 12month period who would utilise euthanasia under the terms of the bill?

**Mr CRAM:** None whatsoever, but I think it would be small. One of the questions, if the Northern Territory goes ahead with this legislation, is whether there will be sudden influxes of people coming here to selfdeliver.

**Mr STIRLING:** I was referring to your own knowledge of the Territory situation, not interstate.

---

**Mr CRAM:** I can only relate it specifically to HIVpositive people within this particular area. It is not a huge number of people. It is very small.

**Mr POOLE:** When you say not huge, can you be more specific?

**Mr CRAM:** In a 12 month period for HIV positive people in this area, we are certainly not talking about double figures.

**Mr POOLE:** Are you talking about the whole of the Territory?

**Mr CRAM:** I am not familiar with the situation for the whole of the Territory.

**Mr POOLE:** But in Central Australia you would not be talking in double figures. Can we interpret that as being, say, 5 to 9 people?

**Mr CRAM:** That would be a hell of a year.

**Mrs BRAHAM:** Not knowing what happens in the terminal stages of the AIDS virus, can I ask whether people are aware right to the end? You talked about advanced directives. Do they actually lose consciousness so they cannot actually communicate and direct people? Would there be a problem in the terminal stage?

**Mr VANDERMORAN:** I would like to answer that. In some cases, dementia does occur in the latter stages of AIDS. The legislation probably would not apply to people in that situation. People have been known to state in their wills that, when they reach a certain stage, they would like to be selfdelivered. However, that is only a small number of people. Quite often, people are quite competent and intelligent within a year of death. It seems that the final months approaching death is the period when people have less control.

**Mrs BRAHAM:** One of the criticisms of the bill is the fact that it talks about people who are diagnosed as being terminally ill within 12 months. Some people say that you cannot really make such a diagnosis. You might say that they are going to die within 12 months but they may last for much longer. Perhaps that length of time needs to be shortened. Or perhaps there is no need for a specified time. In the cases that you are talking about, could you actually diagnose that the patient is going to die within a certain period of time?

**Mr VANDERMORAN:** I think that it is possible. Statistics actually state that once a person receives an AIDS diagnosis, they live up to a maximum of 3 years. My experience with a number of friends who died is that, when a person has been living with an AIDS diagnosis for 3 years, doctors are usually quite comfortable about saying: 'This person probably will not be around in a year's time'. In a statistical sense, that is probably something that can be said.

**Mr POOLE:** Would it be true to say that the majority of people who were 12 months away from the final stages of HIV would probably not opt for an assisted way out, until they got closer to the more uncomfortable part of their illness?

---

**Mr VANDERMORAN:** That is debatable. I have often spoken with people who have been HIV-positive for 6 to 8 years. When they suddenly start getting AIDSrelated illnesses, it is a big shock to the system and they find it hard to cope. Because they have seen their friends die, they know what pain they are going to go through. They know what process they will be going through and they do not want it.

This legislation says: 'I do not have to experience that pain. I can die peacefully without having to go through the pain and anguish and having to put my family through that pain and anguish'.

**Mr CRAM:** Also, they can do it legally.

**Dr LIM:** Can you explain to me how a patient with terminal AIDS HIV dies? What is the pain and suffering and distress that the person goes through in the terminal stages of AIDS?

**Mr VANDERMORAN:** You would probably have to ask each person individually what pain and suffering that they are individually going through.

**Mr POOLE:** Can I just clarify that? When we talk of pain and suffering, are we talking about mental anguish or physical pain?

**Mr VANDERMORAN:** We are looking at both; we are looking at physical pain and mental anguish. The mental anguish is associated with knowing that: 'I looked like this once. Now I look like skin and bone and I am going to die.' The pain can be so intense that you can top up the morphine but still have physical pain. As much morphine as you give, there is still going to be pain. There is both physical and mental pain.

**Mr POOLE:** One area of the bill that has caused us some mental anguish is the definition of 'distress'. Most members of the committee probably presume that, if you are told you were going to die within 12 months, you would be pretty distressed about it. I personally think that 'mental anguish' and 'physical suffering' may be more apt descriptions than 'distress'.

**Mr VANDERMORAN:** I think that is fair enough. However, I think the bill allows for that discussion to occur by requiring the opinions of two doctors. Somebody might say: 'Shivers, I am going to die in 12 months and I want it over and done with now. Firstly, a doctor has to say: 'Yes, this person is competent'. I will refer him for a second opinion.' That provides the safeguard. I would not want to have just one opinion.

**Ms QUINN:** I would like to make the point that people who are diagnosed HIV-positive have adjusted, over many years, to living with the prospect of dying.

**Mr POOLE:** Yes. I guess the same could be said of people who have bad cancer. At the end of their treatment, the doctor might say: 'Sorry, we have not fixed it. You might live 12 months; you might live for 5 years'.

---

**Mr VANDERMORAN:** There does come a stage in the treatment of a person who is HIV-positive and has an AIDS diagnosis when the doctor will say: 'Look, we have done all we can do in terms of treatment. From now on it is just pain management to the best of our capability'.

**Mrs BRAHAM:** You made a strong point about legalising what you call current practice. Are you aware that it is actually happening in the Northern Territory at the moment amongst AIDS patients?

**Mr VANDERMORAN:** I am aware of one person who is HIV positive who would consider the option of selfdelivering whether the legislation is passed or not.

**Mr POOLE:** I think the question was actually asking whether you know of AIDS patients in the Northern Territory who have actually been euthanased?

**Ms QUINN:** Not specifically in Central Australia.

**Mr CRAM:** Not amongst the people in Central Australia who are actually HIV positive.

**Mrs BRAHAM:** What about more broadly across Australia?

**Mr CRAM:** Yes.

**Mrs BRAHAM:** You are probably right. We are only talking about a very small number of people within Central Australia.

**Dr LIM:** With the issue of dementia, it would be more appropriate to extend the 12 month period to perhaps 2 years or longer so that people can decide: 'I am going to end up with dementia, at which time I will no longer be able to competently make a decision. I want to make the decision well before that'. The problem is that you do not know when the dementia comes in.

**Mr VANDERMORAN:** I think you have just described what is basically the living will, whether it will be applied to AIDSbased dementia or another condition.

**Dr LIM:** The living will not apply under this legislation because, at the time of the act of euthanasia, the person must still be mentally competent. That is your problem. You do not know when the person will become demented. So when do you make the choice?

**Mr VANDERMORAN:** You can adjust it to 2 years but there have been HIV positive people who have had dementia for a lot longer than 2 years prior to death.

**Mr POOLE:** I do not think that is the area of concern. The area of concern is that, if you are of unsound mind for whatever reason, you will not be covered by the terms of this bill.

---

We are saying that there is a grey area within the bill in terms of the length of time. Once you hold up your hand and say, 'Me please,' and sign all the forms, the bill does not seem to require a bit of paper that says it has to happen in the next 7 days, the next 7 months or the next 7 years.

As long as the doctors agree that you are terminally ill and it is likely that you are going to die within 12 months, you can sign the paper. However, if you wait 6 months and become demented during that time, you cannot exercise the right. The bit of paper would be cancelled because you are not of sound mind. I am quite sure that the process would involve the person being asked: 'Do you understand that you signed this bit of paper 4 months ago etc?' If the person is judged to be mentally incompetent at that time, the response will be: 'We cannot do it'.

**Mr CRAM:** Would that tend to reduce the number of people who choose to do it or would it push people who choose to do it to actually do it because they do not know if they will be able to do it in a few months' time?

**Mr POOLE:** That is one of the questions the committee is trying to decide.

**Dr LIM:** The question therefore becomes; 'Do you extend that 12 month prognosis to perhaps 2 or 3 years? You can exercise the privilege of euthanasia at the time when you sign the form or you can wait. There might come a day when you think you are ready but you might be diagnosed as mentally not competent at that time. If that happens, nobody will be able to provide the service. Do you see what I mean?

**Mr CRAM:** Would a 2 year waiting period change that?

**Mr POOLE:** Not necessarily.

**Dr LIM:** You could be diagnosed as terminally ill with 12 months or less to live. But as you said, the dementia could occur more than 12 months before you die. It could be 2 years. What I am saying is that, if you are demented for 23 months, the prognosis is that you are going to die in 2 years. However, your dementia could come 1 month after that.

**Mr CRAM:** In that case, I would have to question the validity of the legislation. The euthanasia bill requires you to go through the process and to have 2 doctors look at you and say: 'Yes, this person is mentally competent and would like to be euthanased'. You sign the statements only to find that in a few months' time, it has not happened. You might have 9 months to live. Then all of a sudden you are told: 'No. We are sorry. We cannot do it because you are not competent'. If that can happen, I would question the whole intent of the bill.

**Mr POOLE:** We hear what you are saying, and it is one of the questions the committee has already asked of itself. It is obviously a question that we will raise in our report. We would be looking for an explanation from the proponent of the bill. I guess it will be an area which the committee will probably seek to have amended.

---

**Dr LIM:** It is a vexed area. Then again, looking at it from the viewpoint of those who are antieuthanasia, how is it possible for outsiders to assess whether that incompetent person is in fact quite happy in his or her own head? We judge the person on his or her previous life. The competent person wanting something might become an incompetent person wanting something different. We cannot judge that. We cannot put our values on this person. As the person goes through the process of dementia, his or her values might change as well. So how do you then say that this person really wants to die? You see the difficulty?

**Mr CRAM:** If you will excuse what might sound like a slightly flippant retort, it is the same logic that was used in Aldous Huxley's Brave New World, where everyone was on soma all the time. You could say that it was an absolutely valid society because everyone was completely happy all the time. They were stoned out of their tree. But they were completely happy and they were not miserable. That is presented as one of society's possibilities.

For me, this brings back the simplicity and ease of the living will concept. I think it is unfortunate that it is not covered by this legislation because it can bypass most of these questions. As this legislation stands, I do not think we can answer them. Whether or not we argue over how long the period of time is, the same principle still applies.

**Mr POOLE:** We are not asking you to answer them. The points committee members are raising are points that we feel should be considered. We pick up quite a few of these things in the flow of conversation.

**Mr STIRLING:** I guess we might be creating a dilemma where there might be ...

**Mr POOLE:** There might be none.

**Mr STIRLING:** It might not really exist in the sense that people do like to hang on to life as long as possible and only want to die when the pain and suffering is absolutely intolerable. They are not going to sit around saying: 'Now that I have made the decision, I will wait for 3 months'. If life is so intolerable that they want to die, they are going to want to die fairly quickly, certainly not 2 or 3 months later by which time they may have slipped into a coma and ...

**Mr CRAM:** Or if they have seen what happened to a partner and what they believe will happen to them in a 6 month period of time. If they feel that they are likely to be in that condition in 6 months, they might decide that they do not want to be around at that stage. But they might want to be around until they reach that stage.

**Mr STIRLING:** Correct me if I am wrong, but it has been suggested to me that AIDS as a terminal illness is different to cancer and other forms of terminal disease in so far as the last 12 months can be judged somewhat more accurately. Is that right?

**Mr CRAM:** I do not know enough about cancer to comment.

**Ms QUINN:** I am not sure.

**Mr CRAM:** I have heard of a lot of people who had a number of AIDSdefining illnesses and then became healthy again. They went down again and they came back up again.

**Dr LIM:** Especially with this finding that they are all surviving. That is going to throw a big spanner in everybody's works.

**Mr POOLE:** That depends on how you look at it.

**Mr CRAM:** I am sure that the 5year old is quite happy.

**Mr POOLE:** And I would say that everyone else will be, too.

**Dr LIM:** I am talking about an assessment of what is going to happen.

**Mr POOLE:** Would you like to add anything further?

**Ms QUINN:** I would like to reiterate that it is a question of choice. We do support palliative care but we see this as another option.

**Mr CRAM:** We certainly support people's choice not to follow it as much as people's choice to follow it.

**Mr POOLE:** I think the debate is coming down to a debate between the right to life and the right of choice.

**Mr CRAM:** Yes, it seems that this started out as a process to discuss the legislation, but it actually discusses the issue.

**Mr POOLE:** Are there any further questions? Thank you very much for your time in appearing today, and if you have something you want to put to us in writing, I suggest you do it reasonably quickly.

---

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 16.35 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Frances McKechnie

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

**Mr POOLE:** I call this meeting to order and welcome Ms Frances McKechnie, who is appearing to give evidence. Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case.

**Ms McKECHNIE:** I am quite happy for what I have to say to be said in public. They are my thoughts, perhaps not weighty. They are my thinking on the subject.

**Mr POOLE:** Fine. For the Hansard record, could you please state your full name and the capacity in which you appear today.

**Ms McKECHNIE:** My name is Frances Ingles McKechnie and I am appearing as an individual because of what I feel about this issue.

**Mr POOLE:** What we have been doing, Frances, is to allow people to say what they want to say, after which we ask questions and get a bit of dialogue flowing.

**Ms McKECHNIE:** Thank you for receiving me. It is very easy to say that no one likes to see anyone, especially a loved one, in great pain. Having said that, there is no logic to say that the next stop is euthanasia, whether it is voluntary or not. Certainly, something should be done about pain. I would like us to canvass some of the other options that are available.

I had not thought that I would be against this bill. I thought that I would be in favour of it. But I am not. The bill before the Northern Territory parliament is pursuing the course of voluntary euthanasia but the question that must be asked is: 'Voluntary for how long?'

In Holland, where there was an agreement with doctors allowing voluntary euthanasia, the term 'voluntary' was dropped within 10 short years and now they are allowed to perform euthanasia. In Oregon, where a bill almost identical to this one was made law, a court case is currently under way to determine whether it is allowable under the USA Constitution.

If within a few years the word 'voluntary' is dropped  and I understand that there is no guarantee that it will stay in the legislation  who makes the decision for euthanasia? That is why I am very concerned. I am concerned because we do not live in a perfect world. Those of us with a church background say there is such as thing as original sin, which is man trying to set himself up as god and determine how things should be done.

In the 1980s, we saw what greed could do. People went mad  not only the high fliers but ordinary people  to get money. It would seem that that is still part of our culture today. People will ride roughshod over anyone else to get the money they want for different things. It is something which elderly people  and I guess I have put myself in that category now  have to be very aware of. People suddenly decide that grandma has no quality of life so that her nest egg can be grabbed. It is very easy to make out a case for euthanasia.

The other reason which makes it very easy to make a case for euthanasia is the feelings we experience when we look at the person who is suffering. It is not their feeling. I have done some groundwork talking with those who nurse at the Old Timers, and I have found that not many people ask for euthanasia. In fact, the nursing staff there say that no one has asked for it. Many ask to be put out of pain, but not for euthanasia. People cling onto life in a remarkable way so I think we have to be very careful in the way we handle this.

During this century, we saw the holocaust wipe out people because of their racial origins. It makes you ask: 'Who will be next?' Will it be the aged population because the credit agencies in the USA are telling our government that the money put into social welfare is nonproductive and not making enough? Will it be a question of people's racial origins? Who will it be? It has happened in our lifetime. I believe that, even if there is just a small chink in tightly worded legislation for voluntary euthanasia, it could soon be widened to allow euthanasia generally.

I believe that there are alternatives that should be looked at very carefully. I would like us to start exploring the alternatives to voluntary euthanasia. The first one, which I feel needs to be given much more publicity, is the Natural Death Act of the Northern Territory. One other state, which I think is South Australia, has similar legislation. I just wonder how many of the committee have signed the Natural Death Act. I have signed it.

I signed it because I remember Sir Macfarlane Burnett carrying around a card on the day he turned 70. The card said that, should anything happen to him, he did not want any life support mechanisms. He had had his 3 score and 10 years. If he had another 10, good  and that is what happened  but he did not want money spent on life support systems.

We have that act here. It has not been given a lot of publicity. I believe that, if people thought about it, we could be doing a lot to help people. If you are seriously ill and you survive on your own strength, all right. Otherwise, you quietly die. Until the antibiotics came along, they used to say that pneumonia was the old people's friend. If those are removed, there will be some natural deaths that are not prolonged into dementia and things like that.

The other thing that we do not know much about, and of which we have very little, is palliative care. I think we ought to look very much more closely at that, see how we can expand it and do more to ease people.

Finally, I have listened very carefully to doctors' comments on this on talkback radio. Some of them are very eminent people and others are just ordinary doctors. Again and again it comes up that they really are not trained in the proper use of painkillers. I would like to think that the medical profession would do a thorough analysis of what happens with real painkillers and how effectively they can be used. Most of the polls of people who favour euthanasia show that, when pain is taken out of the context, they are not in favour.

I therefore think that we ought to look at the Natural Death Act, at palliative care, and at painkillers, and see how modern science can be used to help people live with grace and die in dignity. That is all I want to say to you.

---

**Mr POOLE:** Thank you. I think the first point you raised was the possibility of the legislation changing from voluntary to involuntary. Of course, there is nothing to stop anybody changing an act of parliament in the Northern Territory. It would just take another Marshall Perron to come along and introduce another act. It could also be that, if this legislation does not go through the parliament, somebody may reintroduce it in a different format or whatever in a few years' time. There is always the possibility of change to an act. It is just a question of politicians and the written word. Anything could happen at any time in the future. It is a fact of government in our country.

**Ms McKECHNIE:** I realise that.

**Mr POOLE:** It cannot be denied.

**Ms McKECHNIE:** All I am asking is that, in that time, we explore the alternatives.

**Mr POOLE:** Do not open the door, yes.

**Mrs BRAHAM:** Frances, you live at Old Timers, don't you, in the cottages?

**Ms McKECHNIE:** Yes.

**Mrs BRAHAM:** Are you saying that, to your knowledge, the old people out there never actually request euthanasia? I have heard that, when they are ill, the old people prefer to stay in that environment rather than go to hospital. Do you think that is perhaps because the care they receive whether it is called palliative care or something else is the type of care that allows them to die peacefully? Is that one of the options you are talking about in terms of nursing care?

**Ms McKECHNIE:** Yes, I think that is one. However, palliative care or a hospice is something else, and I think it needs to be explored. Maybe they are doing that out at Old Timers through the care they give. However, there are other aspects of palliative care and a hospice that really ought to be investigated. One of the people who would be worth talking to is Professor Ian Maddocks in Adelaide. He set up the first hospice there and has done a lot of work in palliative care. I think if people like that could share their thoughts with us, we might be ...

**Mr POOLE:** We actually have some specialists in that area coming to talk to us. I am not quite sure who they are.

**Ms McKECHNIE:** Yes. Have you asked Ian Maddocks?

**Mr POOLE:** I am not sure if Mr Maddocks is one of them.

**Dr LIM:** He has sent us a submission already but I think he is not coming.

---

**Ms McKECHNIE:** I just happen to know he is a specialist in it. I think the care they get is wonderful but I would not like to say it was truly palliative. I know they just try to love them through to the end.

**Mr POOLE:** Frances, do you think that anybody is practising euthanasia in the Northern Territory anyway?

**Ms McKECHNIE:** I have no knowledge of it. I just have no knowledge of that at all.

**Mr POOLE:** Some people have told us: 'I have administered morphine to fix up his pain ...'

**Ms McKECHNIE:** I have no idea. I have never been given morphine by a doctor.

**Mr POOLE:** Let me put this hypothetical situation to you. I am not sure about other members of the committee but I certainly accept that some doctors are administering quite large doses of drugs like morphine with the intention of fixing the person's pain, knowing that the person's death is a possible side effect.

**Ms McKECHNIE:** That needs exploring a bit further to see what is legally right and what is not. I do not know.

**Mr POOLE:** Under the current laws of the Northern Territory, I guess it is legally right to do it as long as the intention is not to cause death. I wonder what your thoughts are in relation to that. If a situation arises in which doctors are doing that without the patient's consent perhaps because they know they are suffering extremely badly and they administer vast dosages of morphine to diminish that pain, with death the possible result, I think that puts a different connotation on it.

**Ms McKECHNIE:** Yes. I do not know of a case like that. I do know of a woman who was one of 3 sisters. She had not signed the Natural Death Act. When she collapsed, she was rushed into intensive care. She pulled through and she lived to have another amputation. She lived through all that and eventually died at Old Timers. I know that the doctor knew that she had not signed. All that was done for her. It is the opposite case. I just do not know of doctors who have done what you are talking about.

**Mr POOLE:** Brendan Nelson, the President of the AMA, gave a public example. He basically said that he has helped a couple of people over the years. I stress that this was with the intention of helping them with pain management. But in effect the treatment caused them to die. Surely it would be better to have that above the table than under the table?

**Ms McKECHNIE:** I think that is right. That is why I said we ought to look at it. Doctors are asking: 'What is permissible and what is not?' I would have thought that would be part of their training but apparently they feel it is not. These are the issues that ought to be looked at. We all die sooner or later and I think we should leave it at that.

5

---

**Mrs BRAHAM:** Can I just go back to a question I asked previously? Do you think your views reflect those of other residents of those independent cottages in the units? Have you talked about it at all?

**Ms McKECHNIE:** I have talked to some, and they know my views. Most of them have not articulated their views very clearly yet, except for Mr Rankin who is here to have his say. I know that we see cases where we think it would be wonderful. But who makes the decision that that person should die? No one is willing to take that responsibility.

No one likes to see people die in pain. One person who died was found the following day. She was sitting at her dining table with a glass of wine in her hand. We all thought it was a wonderful way to go. Everyone would like to go suddenly like that. But it is not given to everyone to go like that. I think we ought to be able to examine pain and take pain. We seem to want quick fixes for everything. That is not life.

**Mr POOLE:** Are there any further questions, ladies and gentlemen?

**Ms McKECHNIE:** Do you want a copy of what I said?

**Mr POOLE:** Yes, please. Thank you very much for your time.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 16.50 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Mr H D Rankin

**Note:** This is a verbatim transcript. It has not been tape-checked by the editors.

**Issued: Wednesday 26 April 1995**

---

**Mr POOLE:** Thank you for appearing before us, Mr Rankin. I will repeat what I said before. Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. However, witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise now if that is the case.

**Mr RANKIN:** No, I am not worried.

**Mr POOLE:** For the Hansard record, could I ask you to state your full name and the capacity in which you appear today.

**Mr RANKIN:** My name is Hugh Douglas Rankin and I appear on my own behalf.

**Mr POOLE:** Thank you. The format that we have been using is for you to say whatever you wish to say to us. We will ask questions if appropriate but we will try to let you finish before going into a discussion session. We have allowed 45 minutes.

**Mr RANKIN:** I will be finished long before that.

I live at the Old Timers; I have lived there for 10 years and I have been a lay hospital chaplain for the last 12 years. During that time I sat with a lot of people who were wanting to die. Many people want to die but I have only found one person who really asked to die. That is not to say that the others did not ask. They could have asked somebody else; I would not know.

I have sat with many people. I sat with Dr Lim one night when he was pretty ill. That was a long time ago. Generally, I find that people who want to die do not want to die quickly. They are sort of hanging on to life. That has been my experience right through. It does not mean that there are not people who have asked doctors to terminate their lives. I would not know and the doctors would not tell me.

One thing that worries me is the urgency with which this was pushed through in the first place. We were not going to have this type of committee.

You probably know that we have a crisis with the chaplaincy at the Alice Springs Hospital. Our funding has been cut; we are $15 000 short and could use a chaplain. To die with dignity would be everybody's ideal. It is something to which everyone is entitled. The chaplain is called in on most cases where people are dying. He gives the person and their family a great deal of comfort in the last few hours, through the early hours of the morning which is the norm. If that service goes, it will be a great loss.

---

Palliative care needs to be addressed to a greater extent. In Alice Springs we have a palliative care unit but no staff. In Darwin we have palliative care staff but no unit. We hope to get Annie Black down here one day to train the sisters. It would not be much good training me because I am 72. But it would be worthwhile to train people so they can be with other people in their last hours.

I have just done a survey at the Old Timers. People are frightened because they do not understand. I do not believe that enough publicity has been given to this bill and what it really means. The general opinion amongst the old folk at the Old Timers is that, if they get sick, someone will say: 'All right, give them a needle'. It is very hard to get past that feeling.

I was a Commissioner for Oaths and now I am a Justice of the Peace. The only reason for that is that people down there feel they need a JP to sign their papers. That is how old people think. You have to take this into consideration. You have to give more training and more education on this. You cannot just rush in and say: 'We are going to terminate life if people want it'.

I often sign papers which people bring to me in connection with medical and legal matters. I have to ask them: 'Do you understand what you are doing?' Sometimes the documents are 7 or 8 pages long. Sometimes I think they say yes mainly because they want to please me. Half the time I do not really believe that they do understand and that is the part that worries me. When is the cutoff line? When do people say, 'I don't know,' or, 'I do know'? It is very hard for doctors to know where that fine line is. Like Frances, who spoke to you before me, I am very worried that the word 'voluntary' will be knocked out of the euthanasia legislation one day. That is about all I want to say about euthanasia at this stage.

There are a couple of other matters I would like to bring up. A number of issues relating to the hospital need attention. The doctors and the nurses do a fine job but we have no convalescent facilities and no mental institutions. We seem to have leapfrogged those issues and grabbed something in too much of a hurry. I think it simply relates to the Perron family and the suffering of Marshall Perron's mother. No one would wish that otherwise but there are so many other things that should come before that. I think we are just rushing into this without a great deal of thought.

**Mrs BRAHAM:** One of the things that has been raised with the committee is the fact the Territory's population is relatively young. The age profile has only begun to increase during the last 5 or 10 years. In terms of the ratio of aged people to the rest of the population, we probably have more elderly people living in Alice Springs now than we did 20 years ago.

**Mr RANKIN:** That is right.

**Mrs BRAHAM:** The care that is needed for the elderly just has not grown with the demand. That is basically what you are saying. We have not looked at what we really need in the area of care for the elderly. It has suddenly caught up with us now.

---

**Mr RANKIN:** Alice Springs is worse off than Darwin in terms of aged care. We have more aged people per head of population than in the Top End.

**Mr STIRLING:** I have no questions but I would just like to thank you. I was able to see the issue from an older person's viewpoint, probably for the first time. I thank you for that because it has been enlightening for me.

**Mrs BRAHAM:** I know exactly what you mean when you say that an elderly person may sign something one day and the following day might not remember doing so. I think this is the dilemma. Even though they may seem to understand it all, they may just be agreeing with you. It is very difficult to really know what they mean. At that point in their life, they are just very obliging.

**Mr POOLE:** Some young people do that too, when they sign a house contract.

**Mr RANKIN:** Sister Mary Miles from the Old Timers was to attend this hearing. When she had to go to Sydney urgently, I had to step in and do a little bit of homework on her behalf.

**Mr POOLE:** You have done a fine job; thank you very much. All members of parliament will receive a transcript of what you have said today. The idea of this committee is to make sure that everybody has as much information as possible.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 17.30 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr Charles Carter

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

---

**Mr POOLE:** I call to order this hearing of the Select Committee on Euthanasia and welcome Dr Charles Carter, who is appearing as a witness to give evidence.

Other than in exceptional circumstances, witnesses appearing before the committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise now if that is the case?

**Dr CARTER:** No.

**Mr POOLE:** Thank you. For the Hansard record, could you please state your full name and the capacity in which you appear today?

**Dr CARTER:** My name is Charles Richard Carter and I appear as a private individual.

**Mr POOLE:** Thank you. We will adopt the same format as for the other witnesses, Charlie.

**Dr CARTER:** Right.

**Mr POOLE:** I should apologise that we did not give you the opportunity to appear. I am pleased that we have found the time ...

**Dr CARTER:** I realise that papers sometimes go astray. I have made a number of points in my written submission. Most of them have been covered by other people.

In particular, I see the issue as one of rights. I see the provision in the constitution as being important. Even though it may not apply in a directly legal sense, I think the sense of meaning is there. I am considerably distressed at the way the issue has been misrepresented by opponents of the legislation. I can only conclude that it has been deliberately misrepresented in order to frighten people.

One point which I will briefly elaborate relates to a paper published recently in the *British Journal of Social Science and Medicine, 1995*. It is called 'Euthanasia: The Role of Good Care'. The issue of palliative care has been brought up by a lot of people. I strongly support good palliative care and better palliative care. I think everybody does. However, some people tend to regard palliative care as the answer. This paper would indicate otherwise. I quote:

*The view that requests for euthanasia are uncommon in hospices is not supported by the findings. In fact, the findings support the view that people who have had good palliative care are at least as likely if not more likely to request assistance to die.*

2

---

The authors offer an explanation for that, and I quote again:

*Expert understanding of the psychology of dying is one of the hallmarks of hospice care and this is associated with placing a high premium on allowing patient choice. Requests for euthanasia may indicate not that patients are giving up in the face of suffering but they are positively asserting their desire to control events.*

The findings in the paper are not absolutely conclusive. There are some difficulties with the methodology. The committee would probably be aware that research into these kinds of issues is difficult from the point of view of medical ethics and that the research has to be done in a somewhat roundabout way. I think the point is simply that, even though good palliative care is important, the evidence from research would indicate that it is not the answer. It will not to take away the desire of a small minority of people to take control of the timing of their own death when they are in a terminally ill situation.

That is really all I wanted to say, thanks.

**Mr POOLE:** Thank you. Are there any questions?

**Mr STIRLING:** How do you see the relevance of that British study to Australia? Do the findings transport?

**Dr CARTER:** Put it this way. I cannot see any reason why it would not be relevant. The authors say: 'We make the assumption that hospices are providing good care.' We are assuming that the reason for this is not that the hospices are not providing good care. I think that is a reasonable assumption in the circumstances. They assume that the tiny percentage of people who are requesting assistance to die are not doing so because the care is bad. As they say, their interpretation is that people are being counselled about death and, in a sense, are becoming more comfortable with the issue and feeling that they are in a position to make an informed and a deliberate decision.

**Mr STIRLING:** From one point of view, it may not be a surprising finding. A range of witnesses have put the view that, for a very small number of people, palliative care will not assist. Even in the case of best practice palliative care, there is still a small number of people who will not be assisted by it.

**Dr CARTER:** That is possible. The paper does try to examine the factors which are likely to be influencing people's decisions. They find that one of the more important factors is what they call dependency. This basically refers to the physical incapability of the terminally ill person who feels absolutely helpless in a physical sense. There is a correlation between that and the expression of the wish for assisted death. Sheer physical pain may not be the important factor in some cases. There may also be the factor of people feeling totally physically dependent. Good pain relief and good general care may not address that.

3

---

**Mr POOLE:** Are the papers you have quoted from included in your original submission?

**Dr CARTER:** Yes. There is a copy in the original submission.

**Mr POOLE:** And the other thing where you quoted sections of ...

**Dr CARTER:** Yes, that is there.

**Mr POOLE:** Fine.

**Dr LIM:** Charlie, accepting that there will always be patients who are not able to be helped by best practice palliative care, and that we all believe this to be a very small number, is it appropriate for legislators to enact laws for this handful of people?

Usually, laws are made for the majority rather than for the absolute minority? Can you philosophise on that?

**Dr CARTER:** Yes, I would suggest ...

**Mr POOLE:** Like murderers!

**Mrs BRAHAM:** Yes, I was going to say ...

**Dr CARTER:** I would suggest that the legislation is framed in a way which will not affect those people who do not wish to access it. I understand the concerns of people who feel that they might be threatened by the fact that the option is there for some people. I think that fear is completely based on their ignorance of the provisions of the bill. For those people who understand the provisions of the bill, there is no fear. Lorraine made the point that we make legislation about murderers but ...

**Mr POOLE:** Well, I was just trying to make a point in relation to the way we asked the question. The point is that laws are normally made to stop law-breakers. Hopefully, they are made for the betterment of society and applied to a minority of people.

**Dr CARTER:** My answer to that would be along the same lines as Trish Smith's comments. As things currently stand, the legal prohibition on a person's right to decide to assist themselves to die when they are in a terminally ill situation is not acceptable. I see this bill as a step to correct that. I see opposition to this right as based on a desire to impose upon others what I think is fundamentally a religious conviction.

**Mrs BRAHAM:** Charlie, you indicated earlier that you were, I suppose, angry with what the opponents of the bill were saying. You did not really elaborate or give examples.

**Dr CARTER:** The media has consistently reported public statements which talk about people being put to death literally. I could quote some of these from the local newspaper. Clearly, that is not what the bill is about. It is a fact of life in our society that only a small number of people will actually bother to sit down and read the bill. Most people will get their information from the media. The media have been reporting comments from opponents of the bill who are not just implying but actually stating that the bill is going to allow people to be killed against their wishes.

**Mr STIRLING:** Charlie, in terms of the bill's provisions and its workings, have you identified any problems, shortcomings or deficiencies?

**Dr CARTER:** The concern that has been raised today in relation to the time limitation is, I think, a serious one. However, I do take your point that, when people are in a situation where they are going to avail themselves of the provisions of the bill, they are likely to be in pretty dire straits. Maybe some people particularly those with HIV AIDS might be looking a little bit further ahead than most of us because in many cases they have had years to think about it. Perhaps the bill might need to address the issue of how long the declaration remains in force until it is implemented. I would agree with some of the other submissions that have been put forward that the bill perhaps does not go far enough in some areas. I do not want to pursue that because I would prefer that the bill be dealt with as it is.

**Mr POOLE:** Sure. All right. Thank you very much, Charlie.

**Dr CARTER:** Thanks for the opportunity.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 17.45 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr Gregory Winterflood (CONFIDENTIAL)

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 18.25 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative: (on behalf of Life is for Everyone Inc.)

Dr Robert Sassone

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

1

---

**Mr POOLE:** In commencing this hearing of the Select Committee on Euthanasia, I welcome Dr Robert Sassone, who is appearing as a witness to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee should be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise now if that is the case.

**Dr SASSONE:** I have no need to have my testimony kept secret in any way.

**Mr POOLE:** Thank you. For the Hansard record, could you please state your full name and the capacity in which you appear today.

**Dr SASSONE:** Robert Lewis Sassone. I am an attorney, not a medical doctor. I have written on the topic of euthanasia for about 20 years and I have published material for Richard Lammerton MD, who is one of the founders of the British hospice movement.

**Mr POOLE:** Thank you, doctor. Welcome to Alice Springs and to this hearing of the committee. Thank you for finding the time to appear before us.

What we have been doing so far is to allow people to commence by speaking to the committee, whether speaking to a written submission or otherwise, and to follow that with a question and answer session. Of course, if committee members want some clarification of what you are saying, they do have the right to interrupt and ask you to amplify a point or whatever. We have allocated 45 minutes. If possible, we would like you to limit your remarks to about 30 minutes. This will give us the opportunity to ask questions.

**Dr SASSONE:** I have given a book to members of the committee. It was published about a month ago and its title is *How to Protect Your Loved Ones from Pain*. I do not claim expertise myself; I am not a medical doctor. However, I have been writing on this topic for about 20 years. I think that I can go through the issues quite quickly.

Chapter 1 of the book deals with the control of pain. There is a dispute. There is controversy among palliative care experts as to whether or not all physical pain can be controlled. I believe that the majority view and the better view is that all physical pain can be controlled. I take that position in the book, although there are a couple of places where I indicate that there is a contrary opinion.

In terms of your situation, I would like to commence by going through the bill and commenting on a number of points which I believe might bear consideration.

2

---

Going to part 2, 'Request for and Giving of Assistance', it says that you can apply euthanasia or give the person assistance if the patient is likely to die within 12 months. As I am sure some doctor will also tell you, it is impossible to predict that someone will die within 12 months. The most that can be said is that, out of perhaps 100 patients with particular conditions, a majority will die within 12 months. We cannot predict the outcome of a disease for individuals.

I believe that this section as worded is likely to trap people because of a typical condition among those who find themselves with a terminal illness. Initially, you think you have a future. You have made plans for a vacation or for visiting your grandchildren or whatever, and then you get these symptoms and go to a doctor. Suddenly, everything changes.

Where before you had a relatively unlimited future, now all at once you know you have terminal cancer or some other condition that is likely to cause you to die within a short period of time. This usually affects people in the same way. There are different classifications of depression. If I am a sports fan and I watch my team, I might get depressed because someone should have made that shot in the last 30 seconds and they should have won. If I am fanatic, my depression may last 2 or 3 days. Life is full of things that depress us and things that make us happy. For most of us this is not a severe depression.

However, there is another type of depression which is far more severe. That is the type normally treated by psychiatrists. It may frequently require the use of medicines to do various things. New medicines that have come out in the past 10 years include prozac and zoloc and paxil. If I recall correctly, these increase the level of cirotanin in the brain so that the person feels a little bit better. Depression care, however, is in its infancy compared to pain relief. We cannot control it as well as we can control pain.

The transition from thinking you are healthy to realising that you are either doomed or quite likely to die is one of the most depressing things that ever happens to a person. It is normal for people who are informed to at least at some stage feel: 'I would like to get it over with; I just want to die now'. That is quite normal.

However, if they get beyond this stage and almost all of them do it is like looking at a glass and seeing it as either half full or half empty. It depends on your attitude. I am told that it is quite normal for patients, if they are given emotional support and if their symptoms are controlled, except those who are clinically depressed or mentally ill for some other reason, to flip from being so depressed that they perhaps want to die, to turn around and look at what they have left.

So I think that if assistance is given at an early stage without any safeguards, a large number of patients will be caught up because of this temporary early depression. Otherwise, later on, they would have the chance to see: 'I have so much time left'. Such time then becomes precious to them. All of us live behind masks: 'I will not let you know my emotions. I will not let my wife totally know my emotions. I will not let my children totally know my emotions'. Quite frequently, these masks cause problems in our interpersonal relationships.

3

---

We may have a brother who we have been on bad terms with because of something that really was not that important. But we are both too stubborn to change things. Dying time involves some mourning before death and quite frequently if the patient is supported, he will be able to make his peace with the estranged brother or the estranged child. Some wonderful things can happen as we approach death, as the veneer of what we are presenting to the world strips. People come to realise what is really important. Because of this, most patients do not choose euthanasia if you get them past the initial stage, and if their symptoms are controlled.

I question whether I was mature enough, at the age of 18, to make a decision such as this bill might allow me to make.

Moving on to the next page, I am concerned about the definition in paragraph (b), which concerns the rights of the terminally ill. I apologise if I do not have an uptodate version of the bill. I think the definition in paragraph (b) is more vague than it should be. As to paragraph (d), rather than permit the patient to be killed because he is in severe pain, I believe that it is far better to do what you are trying to do here, which is trying to improve palliative care in the Northern Territory.

All over the world, people live in rural areas because they have many advantages. There are many good things about living in an environment like this. However, one of the things you lack is a hospital with a thousand beds and a hundred specialists in all the various areas.

However, I think that in the modern day, in the time that is coming, communication will vastly improve. I dare say that, with the fax machines coming in and the other things, whilst a doctor in Alice Springs may not have the experience of a specialist in Sydney, he will be able to tap into that experience. There has to be some way of setting up good communications so that a person with a problem in Alice Springs or even in a more remote area of the Northern Territory can communicate by telephone and get the best advice available in Australia.

The isolation of your doctors that you have experienced in the past, and the problems that many people may have suffered because they did not have this or that specialist available, will substantially be overcome. You will always have a little bit less specialist knowledge than a place like Sydney but there has to be a way of closing the gap to an extent that people will not choose euthanasia.

I just do not think that there is a patient in this area who must suffer severe pain. I do not criticise the doctors here. In the US, it has been claimed for more than 20 years that we could control all pain for all patients. However, last year the Journal of the American Medical Association published an article which stated that about half of the cancer patients in the US suffer agonising pain without having it controlled. This is in the US where practically everybody lives in an urban area and where we spend a lot of money on medical care.

There are reasons for that. Basically, there is a breakdown in communication between the medical associations and the doctors. At least in the US and in most developed countries,

---

efforts are being made and things are getting better. There are journals such as the Journal of Pain and Symptom Control which do not cost very much. I dare say that, for less than $US100 per year, you could have these journals available in Alice Springs and Darwin. GPs can look at such journals and be well informed about most of the best things that are being done.

As to the severe suffering or distress, those are different matters and I will come to them later.

Paragraph (i) refers to the patient or person acting on the patient's behalf signing a completed certificate. I think that this is a serious threat. You are bringing in is what they call 'substituted judgment'. It is clear to me that you do not have enough safeguards in here to have good substituted judgment. There are some rights that are so intimate that they are not the same as other rights, which someone else can exercise for you. If I vote Labor and I am unconscious, I would hate to have my sister appointed to exercise my right to vote. She is a Liberal sympathiser; that is too intimate. If I happen to say that I really like blondes, I would not want to be unconscious and wake up to find that I have been married to one.

These are ridiculous examples but I believe that the rights involved here are extremely intimate. I have not yet seen legislation or a court decision that establishes sufficient safeguards for someone else to be trusted under conditions as set forth in this bill.

There are no prerequisites to make sure that the patient has been given sufficient care. Dr Lammerton worked with Cecily Saunders, who founded the modern hospice movement. He was the second doctor into it and worked with her in the early days. He is the one who has published the most, and I published his book, *Care of the Dying*. He stated 20 years ago that they can always control all pain but that is not enough because you also have to control all the symptoms. There is nausea and a wide variety of ugly things that we have heard about and do not have to discuss. He said they can all be controlled

As time goes on, our ability to control symptoms has improved. Lammerton says that they can control all of them now. If that is not true now and there is a little bit of controversy about it medical advances are being made all the time. I will get into a few of these later in my talk. In the future, the number of symptoms and the amount of pain that we cannot control is going to diminish. Our ability to treat these patients well is going to increase.

I question whether the details required and the data to be collected will be sufficient to enable you to really understand what is happening if this bill passes.

Those are the major points that I see in the bill. I would now like to sketch out a few areas that are covered in the book. With the permission of the Chair, I will leave the book with you and you can do with it what you want. If you do not want it, perhaps you could give it to someone else who might. If they want it, every member of parliament can have a copy. But there are only 5 of you here.

---

Going into chapter 1 first; there is a good example under 1.4 of how the doctor should analyse the patient's pain. If your GPs do not do this, they should be at least informed that it is possible. Section 1.5 is for laymen, not doctors. It lists the 6 primary tools for controlling pain. Quite frequently, even doctors will skip one of these. 1.6 illustrates pain relief techniques. 1.7 I think is an important chapter. If someone has died with a painful disease such as cancer and their pain has not been controlled, and if they have not used the drugs mentioned, they have not done what they should have done.

It used to be that morphine was the best control for pain. Some people would even say that you should give people heroin, which is basically morphine with a little bit more kick added. It does not relate to pain control but gives them the high. I do not think that there has ever been any need for heroin. Morphine has a disadvantage; it will wear off in 3 or 4 hours. When given as needed, morphine has been guilty of permitting more patients to remain in agonising pain than any other medicine around. That is because 'as needed' pain relief does not work. I explain why in the book.

Fentenyl is much better. It is a fatsoluble medicine. You do not need injections, pills or tubes and you do not need to wake the patient up to give him the pain reliever. All you do is put a little bandaid on the person. Fentenyl is so powerful and soluble that it soaks right through the skin for a period of 72 hours. It is 100 times as effective as morphine which was the most effective pain reliever 25 years ago.

Questions 1.14 through 1.17 briefly outline and this is not for doctors the aspirin class. There are 50 drugs in the aspirin class which basically prevent the pain from getting through the nerve cells that detect it.

Pain can be considered to be a signal. There is a receptor which may be on the skin or inside the body, a specialised nerve cell which detects a condition which means that there is pain there. It is transferred through the spinal nerves to the spinal cord and up to the brain, which differentiates it. Ways of controlling this include nerve blocks, locals, narcotics such as morphine, and epidurals. They are listed on page 7 and I have outlined in here the way they work.

Some pains will respond very well to one medicine. If you have a mild headache, these include aspirin or ibuprofen or something we call tylenol in the US - I do not know if you have it here.

**Mr RIOLI:** How about panadol?

**Dr SASSONE:** Yes. There are 50 of them and they cut it off at the beginning. That usually relieves most headaches but not all. Sometimes you need something more. Sometimes you need codeine, which is a little bit stronger. If that does not work, you move to the morphine class which would include fentenyl, hydromorphone and so forth.

Sometimes, no single medicine is good enough. Sometimes, no two medicines are good enough. Sometimes as many as four different things have to be done to relieve a pain

---

because pain can be complex. Bone pain, for example, does not respond well to morphine. So what do you do? You have to give the patient a medicine in the aspirin class, which will cut off a substantial amount of the pain at the start. Then you get the rest with morphine or some other drug.

The reasons why pain relief fails and why it was formerly frequently poorly treated are stated in questions 23, 24 and 25. The evil of pain is laid out in questions 135 and 136 and the evil of the asneeded technique is dealt with in 138. The US standards for controlling pain are in questions 139 and 140.

In the US, we have done a couple of surveys on the last year of life. This would be the year that would be cut off - I am not saying that it would be a positive year for everybody. However for most it can be. I would like to direct your attention quickly to chapter 6, questions 6.16 through 6.19. Question 6.16 has a quote from Dr Lammerton. Basically he says that, if you care for people properly, euthanasia is neither good or bad, right nor wrong, desirable, repugnant, practical or unworkable. It is just that it is irrelevant. The alternative to euthanasia is proper care.

Question 1.7 deals with why patients change their minds. As I stated previously; 1.8 indicates the curious dichotomy of opinion in Holland where some polls show 70% in favour of euthanasia, but not the people in the nursing homes.

Support for euthanasia in most of the world is about a kilometre wide and a millimetre thick. It is not based on a great deal of thought or knowledge. Most of us have too much information coming to us. We receive perhaps more new information each day than our ancestors may have received in a whole lifetime. The brain cannot hold it all and the average person is making decisions based on just a little bit of information because he is not interested in euthanasia.

In the US, we had euthanasia referenda in 3 states: Washington, California and Oregon. Oregon was 1994; the other two were 1992 and 1991. In Oregon, the euthanasia measure passed 51 to 49. In the other two states, it failed by 54 to 46. In all three places, initial polls indicated that 80% of the people were in favour of it based on this nebulous idea that it would be good to stop this. When they start finding out a little bit more about the alternatives, most of them turn away.

I was involved with the campaigns in California and Washington but not in Oregon. I do not know what they did there, but my understanding of the Oregon bill is that it was much scaled down and that the doctor could prescribe a medicine which the patient would then have to take. However, that conflicts with federal law and so far, it has not been permitted to go into effect.

The cost of caring for the elderly is substantial. Many people will have higher medical expenses in the last year of life than in the rest of their life combined. The overall cost, however, is not that great. Question 17.12 considers this. You are not going to be able to stop, I do not think, if you pass this bill.

At the end of chapter 18, question 18.13, you can read about Derek Humphrey and Peter Admiral. They had no complaints about the Oregon legislation until after it passed. Then they told the Oregon people, 'You are going to have to take the second step'. I have no doubt that the same thing would happen here.

You must be getting some information from the Netherlands. Depending on your definition of euthanasia, 10% or even more of those deaths are not caused by euthanasia. There is a fair inference when you look at the data. I think you should get the Admiral report yourself. It is called the Remmelinck Report. Someone ought to be able to get you the exact report so you do not have to look at someone else's interpretation of it. Depending on your definition of hastening death, there may be vast numbers in Holland whose death is being hastened. Some people are saying that perhaps as many as half do not really consent to this.

But what is consent? I did medical malpractice defence; I had one doctor who had 30 cases pending against him at the same time and it was my job to defend this lovely person. We needed to prove informed consent. There is no provision in your proposed law that has any protection to ensure that the consent is informed. Does the patient have to know about fentenyl? Does the patient have to know about that portion of the medical profession which I think is a majority of those who are informed who believe that all pain can be controlled and that all other symptoms can be controlled? Are you going to set it up so that the emotional aspect is controlled too?

I do not know if you have got the money to do that. If you do not have it, I think that there would be some way to set up volunteers to help these people. You have a lot of old people in every place and a lot of these old people would benefit from helping others. The dying need emotional support and they need someone to talk to, not about anything important. They need to realise that they are loved and that they are important. Selfesteem goes out the window when you are lying in bed dying, but it can be returned.

There are biblical and Christian aspects, which are handled in chapter 21. Documents have come down to us from the early Christians, from just shortly after the time when St John the Apostle first started. Those documents condemn euthanasia. Before the year 1930, I understand that every Christian church and there were thousands of them during all the time that was properly Christian made euthanasia immoral. There were some others which are not regarded as Christian, where death was regarded as a benefit, regardless of whether you were sick or not. The Bible contains words to the effect that 'cursed is he who takes money to kill an innocent man'.

I would now conclude, because I have used approximately half an hour. I thank you and stand for any questions.

**Mr STIRLING:** Thank you very much, doctor. I have only had the briefest of looks through that material whilst listening to you at the same time. Most of it deals with pain ...

**Dr SASSONE:** Chapter 1 of the 20 chapters.

**Mr STIRLING:** ... and this whole question of pain relief. Might there not be reasons other than pain where a person who may well be close to death would want to die?

**Dr SASSONE:** Of course. I do not think that pain causes death directly. The cry for death is caused by depression. The depression itself may be caused by pain or lack of control of symptoms or a number of other factors.

I have a chapter in here that says we can decline all medical care. I am not saying that the patient has to be kept alive and I am not saying that there does not come a time when you can even stop feeding the patient. When the patient is actually into the death process, that is a different matter. For many of us, there will be a time when death has won the final victory and you no longer fight it. I just spoke as I did because of this bill which does not really relate to the very end. You are talking about 12 months before a hypothetical probable date of death. I do not mean you in person; I am speaking to the bill, of course. I apologise for my terminology.

**Mrs BRAHAM:** I know it says 12 months. However, we may really be talking about people who have not made a decision 12 months ahead but are suddenly faced with the terminal stage of illness. Perhaps they are in the dying phase mentioned and all the palliative care and pain relief is no longer working. Where do you see them going from there?

**Dr SASSONE:** They fire their doctor. They sue him for malpractice and they go to a competent doctor.

I think that most of the palliative care experts of the world agree with my contention that the hypothetical situation you gave should not occur, even in the Northern Territory. Palliative care has its complexities, but by telephone a doctor should be able to ...

I am not saying that the doctor would be able to control the pain the first day or two. It may take him a little while to try this or try that - but in a relatively short period of time, a doctor should be able to control it.

You should have fentenyl patches stockpiled in various places in the state, such as in doctors' offices. They are not that expensive and that should cure most of the problem.

**Mr POOLE:** Doctor, this committee has heard some evidence that basically agrees with the general sense of what you are saying that really good palliative care can fix most pain problems. However, in all cases, they said that there are some exceptions where you just cannot do anything for various reasons.

**Dr SASSONE:** Have they given particular examples?

**Mr POOLE:** I cannot remember, to be honest. But they basically disagree with your assertion that all pain can be fixed.

**Dr SASSONE:** Okay; I understand.

---

**Mr POOLE:** They did acknowledge that they are talking about a very minor percentage of people.

**Dr SASSONE:** I deny even that. What I would suggest is that, if this point becomes important, you send me details of the situations. I will forward them to a specialist who claims that all can be controlled and he will send back information on what should be done in this circumstance. If there is a fax number, we can fax it to you.

**Mr POOLE:** Yes. I should say too that the particular person I am thinking of was arguing against the bill and its introduction. They were keen supporters of amplifying the meagre resources we have in palliative care areas.

**Dr SASSONE:** I understand that but ...

**Mr POOLE:** And I guess this affects the other question. It is all very well to compare Alice Springs and probably Darwin with the larger cities in the south, where you have far more extensive palliative care and hospices. We do not have them in the Northern Territory. However, if we do have them in the immediate future, they will probably be in the larger population centres. What are we going to do about the areas that are a long way out? You are not going to have a palliative care situation, for example, in an area like Yuendumu which has 1000 people.

**Dr SASSONE:** If I understand the population situation correctly, the only two cities would probably be Alice Springs and Darwin. People who are too far out probably cannot even get a visiting nurse if they want to stay at home. There are substantial reasons for people wanting to stay home in familiar circumstances rather than in what they might regard as a cold hospital with white walls that are strange to them.

I think, however, that the way to handle it is to increase the knowledge of what can be done under these circumstances. Then those relatively few people who cannot be controlled at home should be given the option of staying home or moving. I do not disagree that, for instance, if swelling or nausea causes pain, the poor guy's wife might not know what to do or might not be able to handle it even over the phone. In isolated areas, there will be people who will have to make the choice as to whether they stay home or move to a place where it can be controlled. You are quite right in that observation.

**Mr POOLE:** Can I bounce another one off you? A number of people have made assertions to this committee that euthanasia is already happening in our society. I say that guardedly and I am not trying to be sensational at all because there is a question about the interpretation of euthanasia. Some doctors will say things like: 'I am strongly against euthanasia but I have administered large doses of morphine or other drugs, with the best of intent'. In this context, 'intent' is the important word. The intent is to relieve the patient's suffering. However, as a byproduct of that, the patient might die. Basically an overdose situation is reached. However, they argue that as long as the intention is to relieve the suffering and not to kill the patient, it is not euthanasia. It is simply the best form of care that they can give.

10

---

To me, that seems ridiculous on the basis that, if these things are going on in our society and in some instances where people are not even asked or told then maybe we should legalise euthanasia purely to bring the problem above the table so we all know what is going on.

**Dr SASSONE:** I point out that the same problem has been faced in every other legislative district in the world. There is no place which has passed a law that is as wide open and has as few safeguards as this bill no place.

If you legalise a little bit of euthanasia, you are not going to be able to stop it or draw the line. I cannot prove that but I can point to the historical record. In Holland it started with 1 or 2 cases. These went to court and the doctor was not severely punished. They now have a situation in which many people are being given euthanasia. There is some argument that many of them are given it without their knowledge. Maybe they would have done something; maybe they would have said so. However, I do not think that the language in this bill sets up a barrier and I am not sure that you can set one up. All you are going to do is vastly increase the number of cases of euthanasia.

In the hypothetical situation that you gave, if the patient is given more morphine for the purpose of relieving the pain, I do not consider that to be euthanasia. If he is given more morphine for the purpose of stopping the patient's respiration so the poor bloke dies, that is euthanasia.

**Mr POOLE:** I am debating that subtle difference in relation to the intention. I am referring to evidence that was given to this committee by a group of doctors against euthanasia. They said the key word was 'intent'. They said: 'If we administer morphine to a patient to relieve their suffering, and we do it with the purest motive which is to alleviate pain if the byproduct is that the patient dies because the dose is so heavy, so be it'.

To me, that is euthanasia, particularly if they have not said to the patient: 'Well by the way, I want to relieve your suffering but there is a possibility that you might die because I am giving you such heavy dosage'.

**Dr SASSONE:** Then there would be no consent to the treatment?

**Mr POOLE:** Yes. I am not particularly advocating this personally. We are just trying to discuss all aspects of it. Surely it is better to have a situation whereby that is above the table and people know exactly what is going on, than the situation where they do not.

**Dr SASSONE:** I would disagree. There are problems if you open it up, as this bill will do, unless you can come up with better language than I have seen anywhere else. You will cause a vast increase in the number who are receiving euthanasia, and you will cause a vast increase in the number of conditions which cause doctors to use euthanasia.

11

---

I got off the plane less than 2 hours ago, and I know that I am making a broad statement about your Territory. However, if you were to examine the doctors here, I think that you would find that some doctors would never have a need to use euthanasia. Other doctors would quite frequently use euthanasia in the form you have discussed or some other form, regardless of what the law is. But once you give legislative sanction to it, the law is a great teacher. You will have a vast increase in the amount of euthanasia. Not only that, I suspect that you will get wide publicity for the Northern Territory as the euthanasia capital of Australia. I do not know if you would want that reputation.

If you legalise euthanasia, you will find that, for an identical set of symptoms, some doctors will consider it appropriate and others will not. Some doctors will start euthanising in large numbers, and will get a reputation for it. Word will get around and you will perhaps have a euthanasiamill situation.

**Mr POOLE:** I do not happen to think that there are doctors in the Northern Territory who are waiting for the law to change so they can run around assisting people to die. I think the percentage of people we are talking about is actually is very low in number. According to our best estimates, we are talking about 14 or 15 people per annum who would fall within the guidelines contained in the bill.

**Dr SASSONE:** If that is all the need there is, what is the need for the bill?

**Mr POOLE:** It comes down to the argument about the choice of the individual or the choice of society. Are we talking about a bill of rights for the people of the Northern Territory, or are we talking about a bill of rights for individuals in the Northern Territory?

**Dr SASSONE:** Once again, I believe that it is better to give them proper medical care than to give them the alternative of euthanasia. Think of it. You are lying there. Your family is in grief; they are seeing you die. You are going to put tremendous pressure on people to end it quicker, pressure that should not be put on them. It is not fair to put it on them. He sees his wife is suffering. You are going to cause a question to have to be faced and the mere facing of it is going to do far more harm than good, I think.

**Mr POOLE:** I say again that the evidence we have been given is that, in cases like that, it often happens anyway.

**Mrs BRAHAM:** I feel that the doctors who have given evidence have done it for reasons of compassion. There certainly has been no indication from them that they are going to suddenly start increasing the number of patients they are treating.

I think you are perhaps insinuating that we have a whole heap of doctors out there who are just waiting for this bill to come along to make their mark in society. I do not think that is realistic. I think doctors are genuine and compassionate. If they ever do get to a situation where they see that there is nowhere else to go, they are doing it for all the right reasons. To me, it is wrong to insinuate that there will be a huge slippery slope of doctors waiting for the bill to become law. If they want to do it, they can do it now. They are doing it, but they are doing it ...

---

**Mr POOLE:** Illegally.

**Mrs BRAHAM:** ... illegally, yes.

**Dr SASSONE:** I did not mean to insinuate that you had a thousand doctors who are waiting with needles.

**Mr POOLE:** No, we appreciate that.

**Mrs BRAHAM:** No, but I am just saying that was what ...

**Dr SASSONE:** What I am insinuating, or trying to express, is that the law is a great teacher. Similar legislation has been considered more than a hundred times in various other jurisdictions and it has been rejected each and every time.

**Mr POOLE:** But that is not a reason for the Northern Territory to reject it.

**Dr SASSONE:** It is an indication that there are some good reasons and some mature considerations that indicate to a lot of people who are knowledgable that this would be a bad line.

**Mr POOLE:** I would suggest to you with respect that in the Northern Territory I have not been in politics that long but I have been in 10 years I cannot think of legislation not proceeding solely because nobody else had such legislation. I think that is a very simplistic view. We would probably say that, in some instances things we have done in the Northern Territory have led Australia. Maybe we do not want to lead Australia or the rest of the world with respect to this particular bill, which is one of the purposes of this committee.

**Mrs BRAHAM:** I thank you for this information. The issue of palliative care has been raised with us over and over again. Doctors seem to need more knowledge and education about pain relief.

**Mr POOLE:** One positive thing about the bill, whether it happens or does not happen, is that there will be much more emphasis on palliative care. So it has done some good.

Are there any further questions? It has been very interesting talking to you. I am sure that we will all read the book with great interest. Just flipping through it, I have cleared up a couple of questions in my mind.

**Dr SASSONE:** Thank you so much for having me, and thank you so much for setting the hearing at such a convenient time. If it had been earlier, it would have been more difficult.

**Mr POOLE:** Good to see you, and we hope you enjoy your trip to the Territory, albeit a short one.

---

**Dr SASSONE:** I appreciate the chance to see the Northern Territory. I am glad you moved the hearing to Alice Springs because otherwise I would not have had the opportunity. Goodbye.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 19.12 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Pastor Mark Hampel, Yirara College

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

---

**Mr POOLE:** On behalf of the committee, I welcome Pastor Mark Hampel of Yirara College, who is appearing as a witness to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses however do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case.

**Mr HAMPEL:** No, it is quite open.

**Mr POOLE:** Thank you. For the Hansard record, could you please state your full name and the capacity in which you appear today.

**Mr HAMPEL:** My name is Mark Alfred Hampel. I am appearing on behalf of 16 other people, whose signatures are attached, to put the case that it is not a good bill. It is really a private thing. However, I do teach in an institution which deals with a lot of teenage Aboriginal children. As a chaplain by profession and vocation, I have a real concern for those kids and for their view of society and all that it has to offer. That is why I have decided to come along tonight.

**Mr POOLE:** Welcome. Mark, we have been allowing people to start by speaking to their submissions. We have allowed 45 minutes from the time we start. I would ask you to try to limit your remarks to 30 minutes so that we will have an opportunity, if need be, to ask questions at the end of the session. If members feel there is a need to interrupt to ask you to amplify a point, we will do so if that is acceptable. Over to you.

**Mr HAMPEL:** Never having appeared before these committees before ...

**Mr POOLE:** Half of us have never actually been on one of these committees. So do not worry about that.

**Mr HAMPEL:** Right. I have written this submission. How do I go through it? What do you want me to do in terms of speaking to it?

**Mr POOLE:** We have the written word in front of us. You can speak to it paragraph by paragraph or say whatever you want to say. It is up to you.

**Mr HAMPEL:** All right. As you can see, I am speaking here on behalf of others who have similar concerns. We are dealing with young teenage kids and we recognise that parliament has a powerful role in setting the way forward for our society. When parliament speaks or makes laws, it has an effect on the whole of society. I am speaking against this bill because I think that it sends very strong messages the wrong way to young kids and to many people in our society.

I have 3 main concerns. The first concern is that the bill is unnecessary. This relates to palliative care. Our century has made great advances in medicine and is the most able of all societies in the history of mankind in terms of its ability to deal with pain. At the same time, there seems to be a widespread lack of awareness on the part of the public and many in the health profession, that palliative care can help people in great pain. I have quoted a small survey by Macgregor Marketing of 400 people in the Adelaide area, 18 years and older. 42% of those people were not aware of the ability of modern medicine to control severe pain. 66% did not know that there were places providing dying patients with pain relief and care but without treatment to prolong their lives.

I quote various people in the submission, including Dr Lloyd Morgan, who rejected the call for active euthanasia because it is unnecessary in most cases and because the choices of dying in pain or being killed are not the only choices available. There is a modern palliative care alternative. Dr Brian Pollard is now working in a hospice in Sydney. In a book which he wrote, he says: 'The fearsome pain of terminal illness can be totally eliminated or at least made bearable by modern medication'. Dr David Cherry of Flinders University says: 'The management of pain is now sufficiently precise that patients can generally decide for themselves on an acceptable level of pain relief. That involves a tradeoff between pain reduction and minimisation of the side effects such as drowsiness'.

I note that clause 6(a) of the bill, under the heading 'Conditions for Medical Practitioner Which May Assist', indicates that all options, including the palliative care option, should be put forward. I have used the word 'ridiculous' in commenting on this, given that in the Northern Territory right now we do not have a single palliative care specialist. We have no adequately resourced domiciliary palliative program and no single hospice. To say that palliative care is an option when it hardly exists simply does not make sense. That is my first point.

As a pastor, I want to comment on the time when a person is dying. Young people die too, or are in severe pain. That is a precious time when very big things are worked through. Sometimes relationships are reconciled and it is basically the last chance for a lot of people. This bill makes it possible for someone in severe pain or in a fit of remorse to decide then and there that they are going to end it all, and it provides them with the means to do it, as many people have wished they could. However, if that were to happen prematurely, I can see that many people in the family would be hurt because they would robbed of the chance to work through these issues under careful pain management.

My second point is that, once started, the practice is impossible to contain. I know that you have probably heard a lot about the Netherlands. Apart from Germany in previous times, it is the only area where this practice is carried out in western civilisation. For that reason, we have to refer to the Netherlands. Hard evidence indicates that, even though Holland has very strong guidelines similarly worded to those in this bill the request to come from the patient, to be well considered, durable and persistent, to be free and voluntary about 1000 Dutch citizens were euthanased without their explicit request and consent in a single year. It has just grown.

That was not the intention of the bill but it happened. I note that the language in the Dutch legislation is similar to that used in this bill. I know that we are civilised and welleducated people here in the Northern Territory, as are the people in Holland and as were the people of Germany when it was tried there. I do not see a great deal of difference between these societies. It is not credible to say that it cannot happen here as it has in Holland because we are civilised countries.

**Mr POOLE:** Are you aware of the fact that there is no legislation in Holland that permits you to kill people? What they have is a tacit understanding with the state prosecution authorities that they will not prosecute people for doing it.

If you read the Netherlands report, it actually comes down in favour of what they are doing over there. There is no public pressure to change it. However, the Australian media has indicated, in reports which have been strongly taken up by Right to Life organisations, that a couple of pages in the report can be interpreted as very supportive of pro-life ideals. In fact, however, any fair minded person who read the report would say that it actually favours existing practice in Holland.

I simply make that statement because I get the impression that you think there is legislation in Holland that allows you to do it. It is actually a case of ignoring the law and not prosecuting.

**Mr HAMPEL:** That is right. I note that there is a strong emphasis in our bill to not punish. Basically it is a change of terminology because ...

**Mr POOLE:** I am sure that Marshall Perron would say to you that his bill cannot be compared in any way with the lack of prosecution in Holland. That is because: (a) he has put forward a bill which seeks to make it become law; (b) they do not have a law but simply agree not to prosecute people; and (c) the guidelines in this bill are very narrow compared to the guidelines used in Holland. That is why we are here: to encourage debate and get your views.

**Mr HAMPEL:** Sure. However, as I read what was written on the Dutch situation, I did note that the language in their guidelines was similar to that used in this bill. There was great similarity of thought and intent in guidelines under which certain behaviour or certain medical intervention can take place. I would not say that they are identical but there are a number of similarities and I think any fair-minded person would see that in comparing the two situations.

In response to your other point; while the Netherlands report was in favour of euthanasia, there was sufficient comment in their reporting which, without any twisting, readily lent itself to the other side of the argument.

In Flinders University in 1991, 2 academics showed that, as we all probably know, there is already a willingness on the Australian medical scene to ignore the law. It is currently against the law to do this sort of thing but surveys have shown that 19% of doctors and

---

19% of nurses have taken active steps to bring about the death of a patient. Of those, 49% had not even received a request from the people who had been euthanased. Even if one person was to be euthanased without their request, that would be very significant. If it happened to be me or something like that ...

**Mr POOLE:** It would really annoy you.

**Mr HAMPEL:** It would! It would be a real shame.

**Mrs BRAHAM:** But don't you think that is an argument for making it legal?

**Mr HAMPEL:** No, I do not.

**Mrs BRAHAM:** It is disturbing that so many doctors are practising it and it is not voluntary. Perhaps legalising it will make sure that the guidelines are more safe and people will not be subject to involuntary euthanasia.

**Mr HAMPEL:** With respect, if we legalised everything that people were already doing, we would legalise stealing. It is wrong and it is illegal but a lot of people are doing it. We do not say: 'Okay some people are doing it so let us legalise it'.

**Mrs BRAHAM:** It is a funny argument. It is not for the good of the people though.

**Mr HAMPEL:** No. Just to follow through, it is interesting to look at what happened in relation to abortion. Backyard abortions were supposed to be a big thing in South Australia a while back whereas in fact there was only a very minimal number. The big argument was to legalise it because it was happening anyway. Of course, there has been a great escalation in a way that had never been seen before.

**Mrs BRAHAM:** But the argument in favour of legalised abortion of course is that it is done more safely and people's lives are not at risk, with the exception of the ones they are aborting, I suppose.

**Mr HAMPEL:** That is right.

**Mrs BRAHAM:** At least there is a lot more care given to the patient. Sorry, I put you off.

**Mr HAMPEL:** That is all right.

I am up to page 3. I note that even though the Northern Territory is full of fair-minded people, many people are agitating for euthanasia and an extension of the principles involved. Even though we ourselves and the legislators in the parliament would not countenance what they are promoting, there are people who are really advocating an extreme point of view. It is being suggested that there is a duty in relation to people who are sick or infirm, and that such

---

people are a burden on society. There are people who are saying those things, and they are sometimes picked up. It is being said, although I know that that is the extreme side of the argument.

**Mr POOLE:** Yes, although it is a valid point.

**Mr HAMPEL:** Yes, it is happening,

My main point is that it cheapens the value of human life. I deal with kids, and with the teachers and staff who work with them. I advise them and encourage them. We value human life. We try and protect the kids against substance abuse and anything that will drag down their lives. There are so many things that do, and ...

**Mr POOLE:** Do you try and protect them from unbearable pain?

**Mr HAMPEL:** We do, and that is why I really advocate the palliative care option, Mr Poole.

**Mrs BRAHAM:** Call him Eric.

**Mr HAMPEL:** It is not the narrow view; it is the broader view. This bill sends signals throughout our society in the Northern Territory, and I really do not think we can ignore that. We are saying that it is okay. It is a complete change of our perspective. Doctors have been interested in preserving life. The army is interested in defending the citizens of a country from people who would come in and kill them in order to take them over. The police force is there to protect. It has been a fundamental principle in our society that life is there to be preserved and protected.

This bill, however, says that those people who have been entrusted with the preservation of life and the enhancement of the quality of life, can now turn around and actually to use raw language assist people to commit suicide or to actually murder them. In the technical terms of the law, that is what it means. It is a very powerful signal that we have changed a fundamental principle in our society. It is a signal that we cannot ignore.

The parliament often sends signals about the language we use. For example, these days we use the term 'the chair' rather than 'the chairman'. This is because of a view about equality of all people. We have enshrined that in language and, in a way, the law sets the standard. In a similar way, a law on euthanasia will say something which is strong.

On page 4, I point out that throughout history in civilised society, based on Canon law and Roman law, through the Hippocratic Oath and the Nuremberg Code ...

**Mr POOLE:** You cannot use the Hippocratic Oath argument. I put that in my newsletter and the good doctor told me that they do not do it any more.

---

**Mr HAMPEL:** There you go. They do not do it. That is a shame; I thought they did. There you go.

**Mr POOLE:** So did I.

**Mr HAMPEL:** The Nuremberg Code, which was developed in relation to the trials of war criminals, and the United Nations, have strongly focused on the preservation of life. It is a solidly enshrined principle in western civilisation. We honour it and protect it. Our rights are founded on life itself; without life, we have no rights. To give the permission for someone to extinguish life is to extinguish the ground of all rights. I quoted Bonhoeffer, who was himself murdered. I think that is just the strongest thing.

If euthanasia was to be legalised by our politicians, they would be responsible for undermining a foundation or principle of our society, namely the inviolability and inalienability of life. I put it to the committee that a law must do more good than the harm than it potentially can cause. It must ensure that more good will come out of it than the harm that will arise in its natural development.

I fear undesirable consequences arising from a bill with perfectly humane reasoning behind it, which is the alleviation of the pain of someone who is dying. I know how things develop. Someone might put in a challenge, saying: 'Only 12 people are going to die within 12 months. That should be extended. I want to die too'. They put a legal challenge and things develop. I am not an expert but I believe that it would grow. The right do die would grow as other rights have grown.

That is about the gist of what I have to say. The submission details other undesirable consequences but you have probably noticed that. We already have a very high teenage suicide rate in Australia. This bill would send them a signal that it is okay to kill yourself or to ask a medical person to assist in your suicide or your death. That is to cheapen the value of life. Someone needs to hold high the standard and say: 'No. Life is too precious; you cannot end it'.

I know you probably cannot see that in the narrow definition of the bill ...

**Mr POOLE:** No, no.

**Mr HAMPEL:** ... but it is just my fear that it would grow bigger.

**Mr POOLE:** I assure you I believe our lives would be that much more simple if we all had principles such as those you adhere to.

**Mrs BRAHAM:** Mark, have you discussed this with the Aboriginal students you teach?

7

---

**Mr HAMPEL:** I have mentioned it. I was listening to someone out Hermannsburg way and he was saying that they did not even know about or really understand the abortion scene in the medical. They did not really understand what was going on there. I have not really gone into it with the students because basically I have not had the time. Although I have not covered it yet, I do teach a unit on social issues such as euthanasia, sexual issues and so forth.

**Mr STIRLING:** Mark, I was interested in your comments towards the end of your presentation. You seemed to be raising the argument of individual rights versus ...

**Mr HAMPEL:** Society.

**Mr STIRLING:** ... the common good. Many committees of parliament have gone before us and, in terms of that question, have come down on the side of the common good. It is a question which each of us, certainly members of parliament, have to face up to at the end of the debate, when the vote is taken on the floor of the House. In terms of the numbers which have been loosely mentioned in the debate, it may involve no more than 15 or 20 people in the whole of the Territory. That has to be weighed. In single year, 15 or 20 people in a population of 180 000 might be seeking help through legislation such as this. Of course, it may not stop at the border. People can come in and there may be many more, so I just wanted to comment on that. Thank you for bringing your perspective to my attention. It provides an important summing up in the whole context.

**Dr LIM:** At the bottom of page 4, you talk about the young people. The bill is specifically very narrow. It relates to terminally ill people. You talk about youth suicide, which is mostly due to feelings of hopelessness, unemployment, homelessness, and the lack of parental guidance within the teenage subculture. How do you see that relating to the bill, which is about terminal illness?

**Mr HAMPEL:** It provides a loophole. If you give an inch, they take a yard, especially in terms of something which was previously forbidden. An example would be the change in the law in relation to bicycle helmets. When there was a blanket law requiring all riders to wear helmets all the time, everybody wore them. However, since the law has been relaxed a little bit, people say: 'Okay, you only need to wear it on the roads'. However, even on the roads, I see heaps of people without helmets. People say: 'They loosened up the law and I can get away with it'. That is just one small example.

**Mr POOLE:** It is an example of euthanasia freedom to kill yourself.

**Mrs BRAHAM:** The right to wear a helmet or not.

**Mr HAMPEL:** See, that is people's right. They want to kill themselves. In a society with a high view of life, the leaders or elders have to say: 'Look, life is too precious. Even if you are in pain and dying, it is still very precious. It is a gift to you. You cannot manufacture it'. I have seen big charts showing how scientists are trying to work out the chemistry of one

---

cell of life. They cannot do it. They cannot produce life. It is beyond them. It is not theirs to tamper with. Sorry, that was not in ...

**Mr POOLE:** All right, thank you. It has been very interesting. You make a good advocate.

**Mr HAMPEL:** Thank you. I realise that I am not as educated as the previous doctor or anything.

**Mr POOLE:** I assure you that I was not being sarcastic.

**Mr HAMPEL:** Thank you for the privilege of speaking to you tonight.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 20.00 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Sandra Clyne, Community Care Nurse

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

---

**Ms CLYNE:** ..My name is Sandra Clyne. I work for the Department of Health as a community health registered nurse. I am appearing here because I was asked to

**Mr POOLE:** Are you appearing on behalf of the department?

**Ms CLYNE:** Definitely not. I am appearing as an individual.

**Mr POOLE:** Fine. We usually commence by allowing people to talk to the committee, to make a submission or to make whatever comment they wish to make on the proposed bill, after which we move into a question and answer session. We have allowed 45 minutes. If you speak for 15 or 20 minutes, that will allow us time for questions.

**Ms CLYNE:** Sure.

**Mr POOLE:** Over to you.

**Ms CLYNE:** , I personally do not disagree with the concept of the Rights of the Terminally Ill Bill. However, I feel that there are some grey areas in the proposed bill and I do find it hard to come to grips with the bill being proposed before we have a palliative care service in Alice Springs.

It is stated in the bill that clients be given the choice of palliative care. We do not have that expert coordinated service in Alice Springs. Our current nursing and respite services are inadequate. I am talking about Central Australia rather than Darwin, which has a palliative care service.

Community nurses and support agencies are frustrated at the inability to provide services according to the definition of palliative care. I have been involved during the past 12 months in trying to set up a palliative care service within the Health Department. Everyone agrees that it is necessary and a priority but we still do not have a position for a palliative care nurse consultant, which is the first step in what we are trying to get. It is always a matter of not enough money. Funding is the usual problem.

The requirement is for a service which contributes optimum quality of life for people who are terminally ill through coordinated medical, nursing, and allied services delivered where possible in the environment of the person's choice, providing physical, psychological, emotional and spiritual support for clients, their families and friends. You probably all know the goals of palliative care by now. I could go through them again if you wanted me to.

**Mr POOLE:** I think we understand them.

**Ms CLYNE:** If these aims are not achieved for a particular client who is terminally ill, and whose pain and suffering are unbearable, my personal feeling is that the client should have the right to choose to end their life in the appropriate way.

2

---

I actually wrote to the Chief Minister when this first came up. I expressed my views concerning the lack of a palliative care service in Alice Springs. I received a reply which I will quote from. He said:

*I appreciate there is concern within the community regarding the impacts of the Rights of the Terminally Ill private member's bill which is currently being debated, on the provision of palliative care services. The bill has not been designed to replace palliative care services but to increase options available to individuals who are terminally ill. The need for a coordinated palliative care service in Alice Springs is recognised, with its strong holistic care focus which respects the person's independence, privacy and involvement in their care and decision-making.*

He goes on to say that he is aware that there is a palliative care room in the hospital, which we know about. The letter continues:

*The lack of an alternative coordinated community-based palliative care service is also appreciated, particularly for those individuals who desire suitable and home-based care. I am very pleased to note the strong community support for the service and in particular the commitment indicated from both the Central Australian Division of General Practitioners and the Northern Territory Anti-Cancer Foundation to further develop and support the activities of those currently attempting to provide palliative care service on an individual basis.*

He then states that:

*A recommendation for a palliative care nurse consultant has been prioritised and forms part of a submission currently being assessed for joint Commonwealth/Northern Territory funding approval. The outcome of these assessments are expected in the near future.*

*Please be assured that it is my best intention that Territorians have access to the best services that can be provided which also includes a range of choice options.*

*Yours sincerely,*

*Marshall Perron.*

Although he is obviously aware of the situation in Alice Springs, nothing concrete has come of it. He basically has committed himself to a certain extent. However, the funding issue remains as always, I am just basically asking the committee, when it puts forward its submission, to point out that we do not have a coordinated palliative care service in Alice Springs. I feel that it is a priority and there are people out in the community who are suffering unnecessarily because of this. I believe that the domiciliary nurses and the GPs are doing their best but do not have the required expertise.

3

---

I also wonder about Aboriginal understanding of the bill. Is it culturally appropriate? Then again, I suppose they do not have to participate if they do not wish to. They do not have to. No one has to, not only Aboriginal people.

As the bill stands, medical practitioners or health providers will be able to assist in voluntary euthanasia. It might be easier if only medical practitioners actually undertake the procedure. If a lethal injection is to be given, they should be the ones to do it. I know that nurses do not have to do it if they do not want to but it still may be better just ...

**Mr POOLE:** My understanding of that provision is that it exists solely to cover people who are actually working in that area so that, if the bill went through, they would not be able to be prosecuted. The doctor would have the exemption but if the term 'health care providers' was not used, the girl who actually picked up the bottle and the hypodermic could be breaking the law.

**Ms CLYNE:** Yes.

**Mr POOLE:** It was never intended that a health care provider would be the one who was actually doing it.

**Ms CLYNE:** Right, but it does not say that.

**Mr POOLE:** Yes, it is a bit of a grey area.

**Ms CLYNE:** I also wondered whether there is a need for a time limit. After everything is requested and consent is given, and the procedures have been followed as set out in the bill, is there a time limit?

**Mr POOLE:** Apart from the 12 month terminal illness time frame, there is no time limit.

**Ms CLYNE:** So you could make a date for 6 months down the track if you were not demented or ...

**Mr POOLE:** I think we have already agreed amongst ourselves that that is another grey area which needs clarification.

**Ms CLYNE:** Yes. I think that is all I want to say. I feel that the people working at the grass roots level, the nurses and the GPs although I suppose I cannot speak for them are really doing their best. However, we just need that additional expertise and a coordinated service to get things going. I believe that, if excellent palliative care is given, there would not be many people who would need to make use of this bill if it goes through.

**Mr POOLE:** All right. Are there any questions.

---

**Mr STIRLING:** I would just like to reassure you, certainly from where I sit on the committee, that we will be making very strong recommendations in respect of all of the concerns that have been put before us in relation to palliative care. I am encouraged by the letter which you received from the Chief Minister. In comments which he was reported to have made about a fortnight ago, there was a recognition of inadequacies in respect of palliative care, which the government would be addressing. I think he has recognised that there has to be a real choice.

**Mr POOLE:** That they are a real choice.

**Ms CLYNE:** That is right.

**Mr STIRLING:** There clearly would not be such a choice if the bill was to become law with the current inadequate state of palliative care. I am interested, however, that at the core of your position, you have some sympathy for the euthanasia option being available.

**Ms CLYNE:** I feel that, even if you have excellent palliative care, there would still be people in need. In my experience of being a nurse for about 30 years, I have found that there are some people who are still in pain or are suffering no matter what you do for them. I think the science of palliative care has improved a great deal on what it used to be. But I am sure that there would still be people who suffer. I do not think there would be many such people if proper palliative care was available and was used.

**Mr STIRLING:** Is it a fair question to ask you to quantify that 'not very many'?

**Ms CLYNE:** I could not; I do not know. It is like saying that people have 12 months to live. That is also a difficult thing to say.

**Dr LIM:** Sandra, I am glad that you read out Marshall Perron's letter because it is quite encouraging in terms of palliative care facilities becoming available. The comment has been made, however, that Holland does not have much palliative care because euthanasia is so freely available. I do not know how you see it, and whether, if euthanasia is provided first, palliative care might be slower to develop. Is that a possibility and how do you see it in Alice Springs?

**Ms CLYNE:** I think it is abhorrent to think of it in that way. I do not think that that would happen. It certainly should not happen. I do not know about you but I certainly would not want to be putting people down ad hoc because there was no other proper form of care.

**Dr LIM:** All right. Why were you concerned that nurses or any other health worker not be active participants in euthanasia. Why should it only be doctors? If the doctors say: 'At such and such a time, I will ask you to do this or that'.

**Ms CLYNE:** That is what I am envisaging. Someone is in their practice and Mrs So and So decides that she wants to die. They will ring up and say: 'Can you go around and ...'

---

**Dr LIM:** That cannot happen because the bill says that the doctor must be present.

**Ms CLYNE:** Okay.

**Dr LIM:** The bill says that the doctor must be present. Do you still have difficulties if the doctor says to the nurse or whoever ...

**Ms CLYNE:** I think so, at this stage. I know from talking to the people I work with that there are so many diverse opinions. It is just incredible. It could cause problems within the workplace.

**Mr POOLE:** As I suggested before, I do not think the idea ever was to include a health care worker in the actual physical process of carrying out euthanasia. It was to cover them in the legal sense because they would be present when it occurred and might, in the legal sense, be construed to have assisted as in: 'Pass me the hypodermic'. I think it was just for legal coverage but it is an area that the committee notes and will certainly take up.

**Ms CLYNE:** It is just my opinion. If I was asked to assist, I just do not know if I could or not. I know other people would say no. Probably a lot more people would say no. If the bill is made law and then gives the right to the doctors to practise euthanasia or assisted suicide or whatever you like to call it, it was just a thought. I do not feel really strongly on it but it is just a thought.

**Mr POOLE:** Do you think much of it goes on any rate?

**Ms CLYNE:** If you describe voluntary euthanasia in similar terms to the doctor in Victoria, who stated that the time was made, the family was present, and other people requested by the client were present, and the client was given a lethal injection whilst in his partner's arms, I personally have not known of such things happening. It is different, I think, in the administration of pain relief. To me, that is not voluntary euthanasia.

**Mr POOLE:** That is the big question mark though, as I see it, as to whether or not it all relates to intent. In other words, is the intent to relieve the suffering or is the intent ...

**Ms CLYNE:** I think the intent is to relieve the suffering.

**Mr POOLE:** They are fine words if you give somebody an injection to relieve suffering and the by-product is that they die.

**Ms CLYNE:** They were going to die anyhow.

**Mr POOLE:** Yes, I acknowledge that. Then it is almost the difference between euthanasia and voluntary euthanasia, particularly if the person does not know.

**Ms CLYNE:** I was going to say that that is not necessarily voluntary euthanasia either.

---

**Mr POOLE:** We have had evidence that that does occur. I am not suggesting that it is widespread by any means but we have had evidence that it does occur. I just wondered what your thoughts were.

**Ms CLYNE:** My thoughts are that that is not voluntary euthanasia and it is not euthanasia either. Pain relief is given and the amount of drugs given are given to relieve the suffering and symptoms. I think probably everyone in the medical profession has ...

**Mr POOLE:** Been in that situation?

**Ms CLYNE:** Yes.

**Mrs BRAHAM:** Sandra, among the people you deal with, how many of them are really aware of the Natural Death Act?

**Ms CLYNE:** I do not think that it is widely known, really.

**Mrs BRAHAM:** Do you think that, if it had a higher profile, people would see it as another option?

**Ms CLYNE:** It could be. All of us, if we feel strongly about it, should basically do that now, promote it now and also declare it. However, I think I am right in stating that the Natural Death Act only states that no extraordinary ...

**Mr POOLE:** Measures.

**Ms CLYNE:** ... measures are taken to prolong life. That does not state voluntary euthanasia. It is a different ...

**Mr POOLE:** Basically it is: 'I do not want to be put on a machine if the machine is the only way I can maintain my life'.

**Ms CLYNE:** Yes, that is right.

**Mrs BRAHAM:** Yet some of those doctors in Victoria who claimed they had done it, were actually doing it under the Natural Death Act ...

**Ms CLYNE:** Were they?

**Mr POOLE:** Yes.

**Ms CLYNE:** Right.

**Dr LIM:** Do you think that the Natural Death Act is something which the whole public of Northern Territory should know about or is it something that needs to be known about only when you are in hospital or suffering serious illness?

---

**Ms CLYNE:** I think that it is probably worthwhile for everyone to know, before they even get seriously ill or whatever, that the option is available and you can fill that out at any time. Obviously, it has to be known in the hospitals and nursing homes, that you have filled out the Natural Death Act.

**Mr POOLE:** There can be a difficulty with Aboriginal patients, particularly if they are traditional people who do not speak English and are relying on interpreters and so on.

**Ms CLYNE:** That is right.

**Mr POOLE:** I can see how, with the Natural Death Act explanation and the Rights of the Terminally Ill Bill, we might never see any such people in hospital again particularly if we ask them to sign an admission form.

**Ms CLYNE:** That is right. The Natural Death Act, and this bill if it goes through, basically provide choices for people who want to use those options. If people do not want to make those choices, there is no need for them to do so.

**Mr POOLE:** All right, is there anything further?

**Mr STIRLING:** You raised the point about the actual assistance and who should be involved - the doctor or other staff. Are there any other practical difficulties on the job that you have thought about in terms of the bill as it stands?

**Ms CLYNE:** Speaking practically, and getting down to the nittygritty, will there be any criteria or whatever for the substance to be used?

**Mr POOLE:** Defined method.

**Ms CLYNE:** I am not knocking the medical profession because I am very fond of them but some doctors do not know how to prescribe proper pain control. Some of them may not know exactly what drugs or whatever to give in the quickest way possible to end someone's life. That needs to be sorted out.

**Mr POOLE:** Yes. We had an earlier discussion about different people using different methods.

**Ms CLYNE:** That is right. I do not think there was anything else. The issue has caused a lot of discussion in the community on every level. I have never known another subject that has raised so much discussion amongst people. It can get heated too; that is the other thing.

**Mr POOLE:** All right. Thank you very much. It has been very enlightening and we appreciate your contribution.

**Ms CLYNE:** Okay. Thank you very much.

**Mr POOLE:** Thank you.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 20.25 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Alison French

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

1

---

**Mr POOLE:** On behalf of the committee, I welcome Ms Alison French, who is appearing as a witness to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do, however, have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case. Do you want your comments to be kept confidential or are you happy for them to go on the public record?

**Ms FRENCH:** They can go on the public record.

**Mr POOLE**: For the Hansard record, could I ask you to please state your full name and the capacity in which you appear today.

**Ms FRENCH:** My name is Alison May French. I am here as a private citizen. I am a recent Territorian, having lived here for 4 years. As a sole carer at home, I nursed my mother with terminal cancer for 6 months when she was in treatment at Peter McCallum Hospital. She eventually died in a hospice. I myself have suffered breast cancer though I have a fairly good prognosis. That personal history gives you some sense of the context in which I have approached these issues with considerable thought and background.

I basically support the concept of the bill. I think that there are some specific grey areas which perhaps need some slight rewording or rethinking. I have 2 particular concerns and I am not sure whether they can be legislated for. However, I think that the intentions behind the bill will not be able to be fully implemented unless these matters are addressed.

One of these concerns an important issue which has been raised repeatedly. It relates to clause 6(e), which makes reference to palliative care. If the medical practitioner cannot advise about palliative care because it does not exist, then this bill will in fact not be able to be enacted. I want to stress very strongly that the provision for proper palliative care is important.

The other thing that I think is very important is education, not only of doctors, particularly in the area of pain control. That to me is very important. This legislation will be creating a new situation. It is not reasonable to expect that the previous training of doctors, who will have to enact it, will necessarily give them the necessary ability. I think that that is crucial.

The third point in relation to education is something I know cannot be legislated for. However, I feel very strongly that there is a need for education in relation to euthanasia, palliative care, how one approaches death, and how one lives with the knowledge of dying. Such issues are best addressed and understood by people well before they ever find themselves in a situation in which they are personally relevant. These issues should be addressed in curriculum in Northern Territory schools, in the widest perspective from Christian perspectives, from Tibetan perspectives and across the full range of the issues.

---

If knowledge of this bill and the Natural Death Act is actually addressed in the curriculum of Territory schools, at the appropriate age levels, it will help people to make decisions for themselves in a much less emotive context and in a situation where they will be able to consider the issues. I feel strongly about that.

In terms of the introduction of palliative care, the wording in clause 6(e) is a little bit loose. It just says: 'including palliative care'. That might mean: 'the lack of ...'. I think it should be worded so that it covers all the avenues of palliative care which have to be available. It means much more than just one nurse. Palliative care is much wider than that. It even follows through to the way architects design hospital buildings, the spaces in which the patient encounters the practitioner, and the ways in which they are counselled. All of these elements are crucial.

I noticed that, in clause 7, the patient is unable to sign the certificate of request. That refers to both practitioners, and I am presuming that they are potentially the first medical practitioner and the secondary practitioner. I feel that the wording is a little bit grey in so far as, at the moment, the second medical practitioner has to confirm the first opinion as to the existence and seriousness of the illness. I think that the second practitioner should also be confirming the following series of 2 or 3 clauses, including the need for the person to be fully informed of all those. It is all pretty logical and I will not spell them out. However, the second practitioner should be part of that.

**Dr LIM:** Clause 6(k) addresses those concerns. It states quite clearly that a second practitioner needs to be fully aware. Okay?

**Ms FRENCH:** Yes, that would be good.

I do not know whether this is nitpicking but I feel that the medical practitioner should be the practitioner who has been monitoring and giving support to the patient over a long period of time and is therefore in a position to fully understand and counsel the emotional and spiritual response of that patient. With the present wording, you could bring in a consultant at the last minute. That person would not know your history, your support structure or the basis upon which the decision is being made. I accepted a lot of the points that the previous witnesses made but I came to a different conclusion. To me, you must have proper pain control and palliative care. You must value life. If all of those things are in place, there will be minimal use of this legislation.

However, there are likely to be a small number of circumstances in which this legislation will apply. I believe that people in those situations should have the right to participate, even though I myself may not necessarily agree with that. For example, even if my mother had had that right, she may not have chosen to exercise it even though her life ended in extreme pain over a very long period of time. I know that she did not have a climate in which she was able to make that choice. I actually suspect that she would have chosen not to do it but it concerned me that she did not have that right.

---

**Mr POOLE:** I am sorry to interrupt you but, with respect to the practitioner, the wording of the bill is quite deliberate in order to avoid the necessity of having your local doctor do it. That is because your local doctor might not agree with it. That would put ...

**Ms FRENCH:** I see the problem there, yes.

**Mr POOLE:** ... the person in the position of saying: 'I cannot have it. I wanted to do it but my doctor does not agree with the system'. In normal cases, it presumably would be your local GP or specialist who has been looking after you.

**Ms FRENCH:** It would be. However, I do think that the person who is making that decision must have consulted more than once, twice, or three times. Even if that practitioner has not been the main caregiver, they must have been part of the continuity of the person's understanding of the death process. It should not be somebody who is brought in at the last minute.

I really do endorse the view that major things happen to people during the death process. The doctor needs to know that the judgment has been considered and is not just as the result of a short term immediate depression or that kind of thing.

I think that penalty of $10 000 is much too low. If you are going to have that penalty, it has to be a reasonable amount.

**Dr LIM:** It needs to be severe.

**Ms FRENCH:** It needs to be severe. Also, although it is a terrible thing and completely nitpicky, it is ludicrous for a person who breaks this law to be fined only $10 000. It is like a token. If you are going to have a penalty, you should have a penalty. I do not know what comparable penalties are in other laws.

**Mr POOLE:** I take the point. If you were doing it on the basis that you want to collect an insurance payment for $1m, $10 000 is not a risk.

**Dr LIM:** Let me put a scenario to you. Assuming that the bill is passed and medical practitioners can do this with this legal protection, obviously some doctors will be prepared to do it and some will not. Suppose that I have been your doctor for the last 10 years but you come to see me and I say that I will not do it. The choice for the patient then is obviously to see another doctor. Over time, a few doctors within a community will be the doctors who perform euthanasia while the rest do not. A clientele would build around those doctors who are prepared to perform euthanasia. That is a scenario which I have in my head. The previous arguments refer to a group of doctors who would be doing it, but other doctors would be doing it.

**Ms FRENCH:** I do not see that scenario panning out. I actually do not see it happening. I do not think that it is like having specialists in plastic surgery, and everybody

---

knowing who they are. I really feel that it is such an extraordinarily painful process. It is a situation in which very few doctors will be participating. I could not imagine your scenario happening.

**Dr LIM:** That is all right. I just wanted to see what you thought.

**Ms FRENCH:** The majority of my experience in dealing with doctors engaging with the terminally ill has been in the Victorian system. My experience with doctors here has related to my good prognosis so I have not bought into that here.

I accept that there have been considerable advances in pain control but I really believe there needs to be major education of doctors. I know of many situations in which a people in the last stages have had prolonged deaths in extreme pain beyond the point at which they have reached a spiritual and emotional catharsis and acceptance of what death is. Those people may well have not chosen euthanasia but my point is they did not have the benefit of legislation and were therefore not able to make that choice. I am just speaking from my personal experience.

**Mr STIRLING:** In your view, did your mother receive quality palliative care?

**Ms FRENCH:** Absolutely. Perhaps if the particular medication that the doctor referred to here had been available, her situation may have been different. She was in a Roman Catholic hospice and, although they were wonderful in the care they were attempting to provide for her, she was in extraordinary pain and had a great deal of difficulty in communicating. I actually do not think that she would have accepted euthanasia. My point is that it was not an option.

It was not something that was discussed when she was not ill, so I did not know what her views were towards it. We had not talked about it as a family and I did not know her view. She was ill for 6 months and she knew that she was dying during that period. It was a very slow process of deterioration. I am sure that a person in that situation goes through a lot of different stages and attitudes. If at the final point before her mind really went, she had confirmed that that was what she wanted to do, I would have known. However, I feel that a support person cannot raise that issue when a person is dying. If the carer raises it, it may create a construct in the dying person's mind. That is far too complex.

If, the whole issue had been up in the air and logically discussed when mum had gone to school, she could have said to me: 'No. No way do I want that' or 'Yes, I want that'. She could have incorporated that into her physical process of dying, which ultimately is about living. I mean, we all live with the knowledge of death.

**Dr LIM:** You are advocating universal education but at the end of it all, you are also saying that it must be a patientinitiated concept.

**Ms FRENCH:** Yes, absolutely.

---

**Dr LIM:** And you are saying that no carer at any time in anybody's life should even raise the issue because that leads to unconscious coercion.

**Ms FRENCH:** Yes, I agree with you absolutely. That is why I argue that the bill should be worded in a very neutral manner which in no way implies that this is the norm that should be followed. It should be presented as an option only.

In the education process early in schools, it can be presented along with all the counter arguments the Christian arguments, the Tibetan arguments, everything. If you understand all the options, you will be able to approach it rationally, emotionally or in any way. However, you will be the person who is making the decision. It certainly cannot occur at the point where the person has the knowledge of being terminally ill. That is too late.

I do not know if you have read the Tibetan Book of Living and Dying. A couple of years ago, I found that book extraordinarily valuable in attitudes towards death when I was contemplating the possibility that my own death might be slightly earlier than I had been expecting. That book talks about the way. If you lead your life from the day you are born with the notion that death is part of the way, then it is just a matter of the way you choose to die and the way your choose to accept it. All of this should not be happening at the tail end of the process. This bill should not be dealing with those final moments. It should be creating a climate in which all people living in the Northern Territory fully appreciate what living and dying are, well before death hits them.

**Mr POOLE:** All right. Thank you very much, Alison. It has been very interesting.

select COMMITTEE **ON EUTHANASIA**

**ALICE SPRINGS COUNCIL CHAMBERS**

**PUBLIC HEARINGS**

Monday 3 April 1995 Opened: 20.45 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives: Parish of Our Lady of the Sacred Heart

Mrs Debbie Brown

Mrs Leslie Reilly

Mr Bill Duffy, Convenor, Sub-Committee on Euthanasia

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** On behalf of the committee, I welcome the following witnesses on behalf of the Parish of Our Lady of the Sacred Heart: Mr Bill Duffy, Mrs Leslie Reilly and Mrs Debbie Brown.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that, for the purpose of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise now if that is the case?

**Mr DUFFY:** No. We are happy for our submission to go on the public record.

**Mr POOLE:** Thank you. For the Hansard record, could you please state your full names and the capacity in which you appear today. We are not using these stand-up microphones. We are using the little microphone on the table in front of you, so could you please project your voices. Thank you.

**Mr DUFFY:** I am Bill Duffy. I am the convenor of the parish council and its subcommittee on euthanasia. As a group, we represent the parish of Our Lady of the Sacred Heart, Alice Springs.

**Mrs REILLY:** My name is Leslie Reilly. Tonight I am representing my husband, who is president of the parish council. He is unable to be here because he is out bush.

**Ms BROWN:** My name is Deborah Brown. I am a registered nurse and a registered midwife. I have a Batchelor of Applied Science in Health and I have some 10 or 11 years experience with palliative care. I have also suffered the loss of a family member with a terminal illness. The parish has asked me to speak on palliative care.

**Mr POOLE:** Thank you very much. We will use the same format, if that is acceptable. You say what you want to say and we will ask questions at the end.

**Mr DUFFY:** As chairman, I will start. Leslie will address you on the impact of the proposed bill on Aboriginal, ethnic and other minority groups. Mrs Brown will address you on the alternative options available to meet the aims of the bill the reduction of suffering and indignity in dying.

I would like to quickly reinforce the issues raised in the written submission. I apologise for the presentation of that document and I trust you appreciate that it was prepared by several authors, none of us very experienced in such matters. In putting the document together, there were a few typos and some disjointed paragraphs. I have here a copy that corrects those points for you. There is no additional information in the copy but it would probably be much easier to scan than the original.

The members of our parish totally reject the concept of euthanasia. We feel that the bill should be defeated on moral, social and legal grounds as well as religious beliefs. We believe that fundamental questions relating to law and society are raised by this bill. The bill would transform the right to decide about medical treatment into a far broader right to control the timing and manner of death. We believe that this is a dangerous policy. Leslie will reinforce the concerns of our minority groups in this regard.

Despite the public perception, the vast majority of individuals who are terminally ill or are facing severe pain or disability are not suicidal. Invariably, those who are suicidal are associated with depression. On treatment, they abandon the wish to commit suicide. I draw your attention to the case of Dr Brendan Nelson and his cancer-ill brother recently reported in the media. Mrs Brown will deal with the palliative care issues in more detail.

The courts and the church have consistently distinguished the right to refuse treatment from a right to commit suicide/murder. The question of euthanasia has been investigated by a number of very learned task forces and committees. In each case, the committee has come down with the recommendation that euthanasia or assisted suicide should not be legalised.

I would like to quickly refer to a number of points Mr Perron made in his second reading speech. His quoting of statistics showing popular support for the concept of euthanasia does not necessarily make the concept correct. The taking of another life, whatever the motive, is intrinsically wrong and is against natural law. Normally, good laws in society reflect natural law. Mr Perron's comment on members condemning some unfortunates in our community to death by not passing this bill is emotive and unwarranted. I would suggest the real blame would lie with the government that does not provide adequate medical or palliative resources in the early stages of the disease.

Mr Perron's dismissal of the wishes of churchgoing people in his speech is selective. If all churchgoing people were to oppose the bill, that would provide a majority of opposition. As he correctly points out, members are representatives of all the people.

Mr Perron stresses the best spirit of medical tradition in his argument against the slippery slope possibility. Earlier in his speech, he cited examples of the medical profession's disregard for the law of medical ethics. He cannot have it both ways. There is no doubt that the law would face the full extent of social inequality and bias that applies to all existing laws. This law would be no different.

Mr Perron's comment that members are not asked to lead public opinion but to catch up is indicative of an abrogation of responsibilities. Members are elected by the electorate to lead. I thank you.

**Mr POOLE:** Thank you.

**Mrs REILLY:** Our submission prepared by the parish council already covers the many issues that we believe will impact on our community here, should the Rights of the Terminally Ill Bill be passed. I would just like to add some additional considerations.

One quarter of our population here are Aboriginal people, many living on remote communities. Given time and the opportunity, they will be carefully and fully informed about this legislation so that they can make their own responses. I would just like to offer an opinion. Given that the western worldview and the Aboriginal worldview of sickness and its causes are so disparate, the notion of euthanasia will promote a further sense of distrust and fear of the medical profession in many Aboriginal eyes.

We also pride ourself here in the Territory on the harmonious relations within our multicultural society. I do not know what attempts have been made to consult with those groups about this bill. Having some involvement with families who have come to Alice Springs as refugees over the years, I have seen the difficulties they face because of differences in language and culture. Even after many years here, some older generation members still express a lack of confidence in their ability to communicate their needs adequately in English and to negotiate our systems.

On a further matter, statements have been made recently which correlate the Dutch statistic of 2300 instances of euthanasia on request that is 1.8% of all deaths in Holland in 1990 to 13 or 14 deaths here. This, however, ignores the totality of the figures in the Remmelink Report. It refers to a further 21 050 deaths or over 20% of the total, where doctors kill patients without request or intentionally shorten the lives of both conscious and unconscious patients. If we relate this figure to our population, I believe the death rate from euthanasia would be approximately double the present rate of deaths from alcohol-related causes.

Evidence has been put before the committee that voluntary euthanasia leads to non-voluntary euthanasia and that pro-euthanasia groups openly support the philosophy of non-voluntary euthanasia.

We also have the question of economic pressures. Indeed, they are already part of the equation. Anyone in the medical profession will have experienced the dilemma of the shrinking health dollar versus the continuing need to support life. For example, determining the priority for a hospital bed when presented with a frail aged patient at the same time as a younger very ill patient. Already in place elsewhere in Australia is the early discharge policy, whereby patients are discharged as soon as possible because of the cost of keeping them in hospital. This further victimises those who are alone and isolated in society, the elderly in particular. It is not inconceivable that, when our generation reaches old age we may have to prove we have a right to live rather than claim a right to die.

If we begin to devalue life according to its judged quality, then the temptation exists for reallocation or reduction of our health care resources away from the weak and vulnerable members of our society: the aged, the disabled and the suffering. It would be a denial of natural justice and an institutionalisation of the scale of value on human life. Only the wealthy would have the means of true personal autonomy.

In conclusion, I would like to quote from an article that I coincidentally came across last week. It was published in the July/August 1994 issue of *Nursing Outlook* and it is titled 'The Future of Death; Death in the Hands of Science'.

*Death is a personal process. Even when afforded the maximum level of support, the dying person slowly or rapidly faces diminished possibilities, systematic loss of connection with friends, loved ones and the daily rituals of life and ultimately, a face to face confrontation with the unknown.*

*On a physiological level, science can ease this process but so far at least, efficiency, sterile professionalism, scientific paraphernalia and technical approaches have not sufficed to replace old fashioned virtues such as love, touch, concern, compassion and human companionship.*

*It is in humanity's best interest to reassess and reassert the humanistic and spiritual dimensions of dying. It would be a strange irony if human creativity and intelligence should combine to shape an increasingly circumscribed reductionistic view of human life and human potential.*

Thank you.

**Mr POOLE:** Thank you.

**Mrs BROWN:** I'd like to open with a quote from a letter from a Dr Karel Guning, a doctor practising in Rotterdam in the Netherlands. The letter appears in the Right to Life flier that was in a lot of people's letterboxes this week:

*We understand that most people want to legalise euthanasia out of compassion with the suffering patient but it is a deadly compassion. There is another way to help. Let us end the patient's pain, not the patient's life.*

I am here to talk to you about the other way, that way being palliative care. There has been a lot of talk about palliative care over the last few weeks and I really have to wonder, given that there is no palliative care in the Territory, how much people really understand of what it can offer. I have experience in the field of palliative care and I have never heard a well managed client ask for death in preference to taking and using every day of life still available to them.

Palliative care, well delivered by trained persons and family and friends, is the only hope of dignity and peace in the dying process. An unnatural death offers only guilt, uncertainty and a deep sense of failure to those who are onlookers and to the dying person themselves. Good palliative care provides a holistic approach to every phase of the dying process. That includes diagnosis, chemotherapy, surgery and the terminal stages of the disease. Holism is a powerful term that encompasses not only the dying person, the disease and the symptoms but also the whole life circumstances surrounding that person. They include the family, the mortgage, the house and friends, just to name a few.

---

The dying person is not simply a disease, as they are often called in hospitals. Rather, they are people who have built whole lives around themselves, which always affect others. Likewise, their disease will affect every facet of their life no matter which stage their life has reached whether they are young, aged or in between. Palliative care aims to affect and be affected by all those life circumstances. For example, a dying aged person will often require more intensive physical support in their care program where a young person may need more emotional and chemical support in their program. Palliative care should always be flexible and ready to meet the needs of the individual clients, their families and their carers.

I have mentioned carers several times already. Who are these people we are calling carers? They are trained medical and nursing staff in the palliative care team. They are also spouses, children and friends. They are people just like you and me. We are all able to participate in the offering of palliative care if we are well coordinated and informed about how our services can best be offered. The palliative care team will provide that advice and monitoring.

Palliative care offers support to the dying in 3 main areas: physical, emotional and chemical support. Firstly, physical support involves the provision of equipment which includes bed pans, commodes, wheelchairs, beds and crutches. It also provides equipment and knowledge in dressings, administration of oxygen and a coordinated network of carers as the disease progresses. The dying need all of these things to make life more comfortable and independent and they often allow for the preservation of personal dignity for as long as possible.

Emotional support concentrates on enabling the terminally ill to discuss their fears and concerns with others. The palliative care team can then offer advice and coping strategies to deal with each crisis as it comes along.

So who offers the counselling? We have: the palliative care staff themselves, including doctors and nurses who are trained in the field of palliative care; pastoral care workers from various churches and all religions; social workers; trained counsellors and psychotherapists who are trained in the dying process; the family doctor, who may not be the palliative care doctor at this stage but is still usually a very good friend; and family and friends.

Once a need for further counselling is identified, the palliative care team can arrange for someone to listen who is best able to help. Often the dying find it difficult to discuss their fears with their families, who may find it too confronting and sad to listen. We all need someone to talk to at some time.

Chemical support, as the name implies, concentrates on the use of various drugs to alleviate symptoms such as nausea, vomiting, depression, stress and, of course, pain. The type and quantity of drugs used are determined by the dying person's needs and wishes. Assessment is very much an individual process. Chemical support can be offered effectively in hospital or in the home using a variety of techniques such as tablets, injections, syringe drivers, oxygen therapy and tubes for rehydration. Its aims are to achieve greater comfort by reducing

symptoms and alleviating pain for the client. By making the client more comfortable, you automatically reduce stress and suffering for the onlookers of the dying, usually their family and their friends.

If you have ever considered that pain relief is all that palliative care involves, then you are very much mistaken. Palliative care is a specialty area of health services and staff need to be trained in every aspect of treatment and care if it is to be truly effective. It is not depressing murk but truly the greatest gift one human can offer to another.

The government will not get any returns from offering quality palliative care. It will certainly incur some costs in setting it up and ongoing maintenance but is it not the purpose of government to concern itself with the needs of every Australian, which must include dying Australians?

Here in Alice Springs and the rest of the Territory, there is no effective palliative care on offer. Why are dying Territorians so easily ignored? Being an isolated community should not prevent the people of Alice Springs having access to all they need. We need firstly doctors. That does not mean every doctor in Alice Springs. It means those who are interested to be trained in palliative care and specific drug use. We also need nurses who are trained and skilled in identifying palliative care needs and counsellors trained in the needs of the dying.

Palliative care aims to make life more comfortable and helps to preserve the dignity and self worth of the client. When a dying person asks to end it all, are they really saying that they simply cannot handle the pain and the isolation any longer?

People will always be offered support by governments in many areas such as during pregnancy and childbirth, during trauma and abuse, during difficult marriages and during times of tragedy. Why not offer comprehensive support during the dying process as well? Are these people less deserving of our help? Humanity needs governments who are willing to care about people, not to throw them away. Marshall Perron's bill is not for the good of humanity. Thank you.

**Mr POOLE:** Thank you. Are there any questions?

**Mrs BRAHAM:** Leslie, you and David have a lot of experience in Aboriginal communities. Can you give any advice to the committee on how we should be seeking their opinion, educating them or getting the message across?

**Mrs REILLY:** I think time is the biggest thing. With the current time frame, it is impossible for people on communities to have any knowledge or understanding of this bill.

**Mrs BRAHAM:** In those communities, have you had any experience of suicide or euthanasia being practised in Aboriginal culture?

**Mrs REILLY:** No. I have experienced people having a mistrust of whitefeller medicine and using, in effect, a witch doctor. In fact, when my mother-in-law came to Santa Teresa and was dying of cancer, they actually took her to the witch doctor. For some inexplicable reason, she was pain free for about a week afterwards. So who are we to say which culture has the answers? Indeed, we do not.

**Mrs BRAHAM:** You are worried that this bill will create a greater fear of doctors and hospitalisation.

**Mrs REILLY** Yes. People may think that someone is going to give them a needle or a tablet that will kill them. This is because they do not feel in control of the circumstances they are in.

I have mentioned to you a situation which occurred 12 months ago in a palliative care room in the hospital. The lady concerned, although Aranda, had very long experience of living with European people from Charles Creek to Arltunga and Santa Teresa, and her English was as good as yours and mine. I do not know why proper pain relief was not offered until she was diagnosed terminal, which was in the last weeks of her life. When it was given, as far as I could see it was close to meeting the needs of pain relief. The biggest problem, however, was communication. She was not listened to and she was not heard. She had a fear of being sent home on that road in her condition. Twice it was suggested by hospital staff that she might want to go back out. From an emotional viewpoint, it distressed her enormously that she might be physically transported back. She was terrified of the effects of that ride.

**Mrs BRAHAM:** It is our understanding that many people would prefer to die back in their communities rather than in hospital.

**Mrs REILLY:** I think that it is an individual thing. We cannot assume that. Obviously, that is what was assumed in this case. We all need an individual communication. Every one of us is different.

**Mr POOLE:** You quoted some figures from Holland and extrapolated those to the Northern Territory situation. Do you honestly believe that we have doctors here who are just itching to get at many hundreds of people?

**Mrs REILLY:** I just think human nature is human nature. The Dutch thought they had the controls. Apparently the Dutch government was quite horrified at the findings of their own report.

**Mr POOLE:** But they are not horrified enough to change the situation. According to my understanding of the current situation, there is no move in Holland. The report has been widely accepted. If you read the entire document, you would have to say that it favours euthanasia, apart from 2 or 3 pages of statistics that have horrified everybody.

**Mrs REILLY:** I believe that there is a very strong antieuthanasia movement there now.

---

**Mr POOLE:** I think there always was. However, it is obviously a minority. Otherwise, the government would have either started prosecuting people or reinforced the law. The existing law does not allow them to ...

**Mrs REILLY:** Maybe they are in such a quagmire that they do not know how to get out of it. One of the parish workers here has a Dutch husband and his mother, who lives in Holland, is very elderly. She is very afraid of being sent to a nursing home. I can only give you that one personal instance because I do not know ...

**Mr POOLE:** Do you think that Marshall Perron's bill would cause Territorians to suddenly become scared of going to a nursing home?

**Mrs REILLY:** I think we could start on that road. Without getting into the moral considerations, we already have a precedent in the shape of abortion, which is termination of a form of life. When that was introduced many years ago in Australia, there were very narrowly defined provisions under which it could be carried out. As everybody knows, those provisions are now very broad. All such incidences during this century have led down a road which no one seems to have been able to stop, except for the Nuremburg trials which led to the hanging of doctors for this practice. In 1995, we are supposed to be more enlightened. But how can you say that the provisions will not be broadened in 5, 10 or 15 years' time? You use the definition of people who are in great pain and suffering. It is not only the terminally ill who are in great pain and suffering. Many other people are in that category and they may not die tomorrow, next week or next year.

**Mr POOLE:** Yes. Do you admit that, if the terms and conditions of the bill proposed by Marshall Perron are adhered to strictly, it will really apply only to quite a narrow band of people?

**Mrs REILLY:** I believe that it is impossible that it will stay within those confines.

**Mr POOLE:** That was not the question. The question is: do you believe that the bill as it is written today really applies to a very narrow band of people?

**Mr DUFFY:** I do not believe it does, Eric. I can see that an attempt was made to narrow it down but I think that there are enough discrepancies in the bill, as it is now written. I just believe that it is a matter of drafting.

**Mr POOLE:** In what way, Bill? What do you identify as the discrepancies? That is apart from the slippery slope argument. I am not advocating it. We are trying to present a case to parliament that gives the pros and the cons for the bill, if I could put it that way.

**Mr DUFFY:** Yes.

**Mr POOLE:** I think that the case probably fails a bit if we simply say that it could go from voluntary to involuntary, when the bill specifically says that you have got to hold up your hand.

---

**Mr DUFFY:** I am talking more or less from memory now. I did not bring any joggers along on this one. The lack of a cooling-off period means that a person who is not under pressure other than having been told that he has say 10 months to live, may have all his faculties at the time when he signs. When he gets down to the last 3 or 4 weeks and has perhaps lost some of his faculties, there is no way back for him.

**Mr POOLE:** But there is. The bill specifically states that the doctor is not be allowed to carry out the process if the patient has lost control of some faculties. The doctor has to certify that the patient is in full control of his faculties. There is also a clause in the bill that specifically gives the person the right to rescind.

**Mr DUFFY:** Yes, I know that. But the practice of that particular clause relies on the person having sufficient control of his faculties to rescind. What I am saying is that ...

**Mr POOLE:** No, it does not. The bill specifically says that the patient must be of sound mind. Clause 6(m) states that: 'At the time of assisting the patient to end his or her life, the medical practitioner has no reasonable grounds for doubting that it continues to be the patient's wish to end his or her life'.

**Mr DUFFY:** Right. Well, that is okay. If you go to clause 8, which covers the right to rescind the request, there is a requirement that the patient is more or less in full control of his faculties, the same as when he signed it. However, the deterioration of the patient during the illness may mean that he is no longer able to communicate this to his doctor. That is the point I am trying to make.

**Mr POOLE:** I think this committee would take that as a grey area if other people felt like you. I personally think the opposite applies. If somebody is lying there and cannot talk or communicate, I would say that such a person does not qualify. The bill quite clearly states that they have to be mentally competent at the time, not at the time of signing, but at the time when the act is carried out.

**Mr DUFFY:** Right. That is fine, Eric, and I understand that. Our problem is that we do not believe that that will be the practical application of that.

**Mr POOLE:** That is fair comment too.

**Mr DUFFY:** We believe that it will have a different theme.

You asked Leslie whether she thought the bill would introduce to Territorians a feeling of not wanting to go to the hospital. We have a number of people in our parish community who both live at the Old Timers and who work in that environment. Even without being passed, this bill has introduced a real fear amongst those parishioners that they are being got at. I think that that will escalate if the bill becomes law. Although there may be a very narrowly defined target group at this stage, as Leslie mentioned in the context of the abortion debate, there will be a lot of Territorians who will not do their dying in the Territory.

---

**Mr POOLE:** The reason I asked the question is that we had evidence earlier today from someone at the Old Timers who says exactly the same thing as you. I was just looking for some reinforcement.

**Mr DUFFY:** Right, thank you.

**Mr POOLE:** What do you think about the fact that, according to some evidence given to this committee, it is apparently already happening in the Territory and that doctors are committing acts of euthanasia?

**Mr DUFFY:** Quite frankly, I believe that they are and that the authorities should be pursuing that as hard as they can go. I do not know of instances, Eric. My wife is a nurse and she practised in geriatric and community nursing. We have not come across any particular instances.

**Mr POOLE:** Forgive me for playing the devil's advocate but I see it as our role to address all aspects of this bill. We have had evidence that basically suggests that some doctors administer overdoses of drugs. The crux of this is the intention to relieve pain and the side effect is that the patient actually dies.

**Mr DUFFY:** Yes.

**Mr POOLE:** To me, that almost sounds like involuntary euthanasia let alone voluntary euthanasia. Of course, the argument is that the intention is not to kill the person but to relieve their pain and suffering. If I wanted to really play the devil's advocate, I could say to the doctor concerned: 'Did you explain to the person that you could relieve their pain and suffering by administering a really large dose of morphine but that such a dose might be enough to kill them? If you did not explain that, why not?' I would suggest that, if it is not explained, in a moral sense it really falls within the category of nonvoluntary euthanasia.

**Mr DUFFY:** I agree wholeheartedly with you, Eric. If you have had evidence about it, no doubt it is happening. I believe that it demonstrates the lack of training of those doctors in palliative care issues and the management of the process of dying. There are people here who are more expert than I am, but from what I have read I understand that the modern trend in palliative care no longer focuses on massive doses. I believe that there are many wellintentioned people looking for an answer which their current training and skills do not provide. As a community, with government support, we should be increasing that skill and knowledge so that we do not have to put those sorts of pressures on the doctors.

**Mr POOLE:** Yes. I am certainly not disagreeing with what you are saying. However, situations differ from place to place. There is a difference between living in the Northern Territory and living somewhere in the Adelaide Hills, for example. Even within the Territory, surely you will never have palliative care in places like Hermannsburg or Nyrippi which matches what might be available in a place like Alice Springs or Darwin.

**Mrs BROWN:** Surely the flying doctor service established in the Territory can also provide palliative care to the remote communities. If the flying doctor is used for health, why can it not be used satisfactorily for the dying?

**Mr POOLE:** With the greatest of respect, I think that is fairly naive. It is hard enough to get the funds together to get the flying doctor service to fly out to rescue someone who is seriously ill in the Northern Territory. I am not debating the rights or wrongs of the situation but they spend half their lives raising money. I do not think you could ever expect the flying doctor or a similar organisation to provide palliative care out in the communities of the Northern at least, not to a satisfactory level. People will have to come to town. The problem is that, when people reach that stage, the majority want to die at home. Certainly Aboriginal people want to die in their own country.

**Mrs BROWN:** I am working at Old Timers at the moment and my experience of Aboriginal people is that that is not the case. The Aboriginal communities do not want them to die at home because that means they have to have a smoking ceremony and they have to move on. I am talking about traditional Aboriginal people. They are learning quite quickly that you can pop them on the flying doctor plane and get them into town and out of the community. In those circumstances, the community does not have to move and go through the traditional processes. We have 4 ladies at the moment ...

**Mr POOLE:** You are completely at variance with evidence that was given to the committee this afternoon.

**Mrs BROWN:** We had 2 ladies last week who went to Kintore. The families returned them and have asked that they do not come back because they are very aged and they do not want to care for them. They do not want to have to go through the processes that they normally use. That has happened before.

**Mr POOLE:** You surprise me because that directly contravenes evidence we were given this afternoon that such people want their families around them when they are dying and they want to do it in their own country.

**Mrs BROWN:** That may well be the case. It may be what the dying person wishes. But it is not necessarily what ...

**Mr POOLE:** These people obviously were not dying. They were giving evidence to the committee this morning. At any rate ...

**Mr DUFFY:** Could I just go back to your point on the provision of palliative care service centres? I have worked in the government long enough to know that there are questions of funding and so forth. Given the budget situation, we have no hope of providing a consistent level of palliative care right across the community. However, there should be no problem with the Northern Territory government trying to develop a centre of excellence in terms of palliative care. Obviously, as the Territory's capital city, Darwin is the place for it to go.

12

---

I believe that if the Territory government took that approach and established a centre of excellence, a flowon effect would spread through the community and would have a very positive impact to change the situation of people who are dying in the community at the moment without the help of this. We are not asking that there be palliative care centres and expertise set up in every community. That is not what we are asking. We are asking that the Northern Territory government support the establishment of a centre of excellence, a really good facility that will be recognised for what it is. Through the ordinary processes, that will filter down to the community level.

**Mr POOLE:** I believe that the one positive outcome of this exercise will be a fair amount of chat and hopefully common sense in relation to the area of palliative care. Let us assume, for the sake of this exercise, that there is a government commitment in this financial year to do wonderful things in palliative care. I personally believe that palliative care should be just as available to people in Nyrripi as in Alice Springs or Darwin. To my mind, it would have to be a broadly based community service. Assuming that did happen, where does it leave the bill? If you have the option for palliative care and you have all the great things that it can do and I accept that all the evidence we have been given about that is very truthful there will still be a percentage of people for whom it does not apply and who want this choice of euthanasia.

**Mr DUFFY:** Right. That is where we believe that the bill is dangerous. The whole question of one person taking another person's life is a threat to the whole community. Irrespective of whether or not palliative care issues are addressed, the fundamental thrust of this bill is very dangerous socially, morally and legally.

**Mr POOLE:** What you are saying is that palliative care is really a bit of a red herring.

**Mr DUFFY:** Yes.

**Mr POOLE:** The real question that the community is debating is whether or not you have freedom of choice or right to life.

**Mr DUFFY:** Yes. We see that there is a great deal; of difficulty about the definition of euthanasia. Even amongst our own parishioners, in spite of all the workshops and discussions we have had, people still have difficulty in distinguishing between euthanasia and easing somebody's way of dying. That is why we are advocating palliative care as an alternative, so that the government can pick up on all these people who are confused. However, the reality is that the bill as it stands is a dangerous bill. It threatens every citizen in this country.

**Mr POOLE:** Okay. I am hogging all the questions here.

**Mr DUFFY**: And I am hogging the answers.

13

---

**Mr STIRLING:** Given that the whole question of palliative care has been such an issue before the committee and in the community at large, one wonders where the Minister for Health has been in the debate. There has not been a squeak from that office. Certainly, the Chief Minister in recent weeks has gone a long way towards recognising the concerns of the community and making some commitment. The whole question of provision of palliative care will be considerably strengthened and that commitment will stand whether this bill is enacted or not. That is on the record. Eric made the point that, at the end of the day, that is at least that one very positive thing to come out of this discussion.

**Mrs BRAHAM:** There has certainly been a lot of activity in the Health Department. The community health people, the anticancer people here, and doctors generally have been undertaking processes and submissions for the budget and coming up with a mixture of concerns not just through the Northern Territory government but through the Commonwealth. That has been going along with the debate as well. It is not just relying on the Northern Territory government.

**Mr POOLE:** You are not reacting to Syd's shot at the Minister for Health on this bipartisan committee, are you?

**Mrs BRAHAM:** Oh, no.

**Mr STIRLING:** I just think it is an interesting omission at this stage of the debate.

**Mr DUFFY:** Certainly, we believe that it is good that this debate has highlighted the palliative care issue. It very much falls in line with what we believe the dying process should be.

**Mr POOLE:** I guess one can only wonder where the debate would be on the euthanasia bill if we had all the palliative care provision that we obviously need.

**Mr DUFFY:** Yes.

**Mrs BROWN:** I think the bill as it stands is quite discriminatory in so far as there are a lot of other people suffering other diseases out there who may want to have themselves euthanased. I think the bill leaves itself open to be contested in court time and time again until we have euthanasia on demand. Then, where are the rights of the people who are terminally ill? Are they going to have to prove that they have a right to live or will they be expected, at some period in time, to euthanase themselves?

I also think that there will be death clinics in the Territory. There are abortion clinics today where people specialise in abortions because a lot of doctors will not go through with it. I think that there will be doctors' clinics specialising in death death clinics or whatever and I think this will all happen through the courts. This will be contested. There will be people out there who feel that they should also have the right. There will be doctors who are prepared to go through with it. Doctors are human. They are subject to the same sorts of corruptions that

---

we face every day. They too can be corrupted. That is why we have jails and there are doctors in jail too. The protocol here is not good enough to stop this sort of thing happening.

**Mr STIRLING:** I think that is a very interesting point. There is a question of possible legal challenge from groups who feel that they have been excluded from the bill in terms of the 3 points which it covers pain, suffering and distress. There are many other ...

**Mr POOLE:** You were there when we asked that question of the Commissioner for Human Rights.

**Mr STIRLING:** Well, we will still be seeking ...

**Mr POOLE:** She answered the question and basically said: 'No, the point of law just does not apply because it is Northern Territory legislation'.

**Mr STIRLING**: What about all the groups that will chase it through the courts? It will be legally challenged. If this is enacted, I think ...

**Mr POOLE:** But not under the human rights legislation.

**Mr STIRLING:** Well, whether under the human rights legislation or not.

**Mr DUFFY:** You might not need to go to human rights to do it, Eric.

**Mr STIRLING:** I think there is a very valid ...

**Mr POOLE:** I am sorry. I am not making myself clear. We asked the question of a witness before this committee who should be in a position to know. She was quite emphatic that it would not be possible under the Northern Territory AntiDiscrimination Act because it is a Northern Territory statute. That would be the law. One piece of legislation does not override another piece of legislation. If it excluded people because they were Aboriginal or Roman Catholic, for example, that would be a different matter. But that would not be the case if they were judged not to be mentally competent.

**Mr STIRLING:** Let me go back again. There are groups in society, mentally competent people, who are suffering pain and stress every day of their lives. They are not terminally ill and that is where they do not meet the requirements of the bill.

**Mrs BROWN:** You can concede that their disease is going to kill them in the end but ...

**Mr POOLE:** It is the same as the situation in respect of other laws. You cannot challenge the Northern Territory law that says you cannot drink until you are 18 years old. This bill says that you do not qualify to take advantage of its provisions unless you are terminally ill. There is no difference.

---

**Mr STIRLING:** Well, let the courts decide on this question of terminally ill. It might be the early stages of multiple sclerosis but it is still a terminal illness although it may take many years.

**Mr POOLE:** I am not a legal eagle. All I can say is that I asked the question of the AntiDiscrimination Commissioner and she said: 'No hope'.

**Mr STIRLING:** Under that.

**Mr POOLE:** Under Northern Territory law.

**Mrs REILLY:** But laws can be amended.

**Mr POOLE:** Most certainly. Although I do not believe it makes the slippery slope argument any stronger, people have to accept that whoever has the numbers in the Legislative Assembly can change any law of the Northern Territory.

**Mrs REILLY:** That is precisely why the bill is dangerous.

**Mr POOLE:** That is precisely why you are doing what you are doing.

**Mr DUFFY:** Yes. That is precisely why.

**Mr POOLE:** That is our democratic right and if people do not like what is happening, they change the government. This is an unusual situation in so far as the bill is not being promoted by the government. In fact, there would be as many divisions within the government as there would be in the opposition, I am sure.

**Mr DUFFY:** As in the community.

**Mr POOLE:** Yes. Are there any further questions?

**Mr RIOLI:** Leslie, does your parish council cover a fair area in the Aboriginal community?

**Mrs REILLY:** I am not on the parish council, Maurice. My husband is. The parish council relates to Alice Springs.

**Mr RIOLI:** Just to Alice Springs itself?

**Mrs REILLY:** Yes.

**Mr RIOLI:** Right. You mentioned earlier that there was a mistrust of the medical profession by some Aboriginal people.

**Mrs REILLY:** I have lived at a number of communities Port Keats, Santa Teresa and Lake Nash for about 14 years from the mid 1970s. I just feel that Aboriginal people did not always trust the European version of medicine. They have strong beliefs in their own as well.

**Mr RIOLI:** They have their own.

**Mrs REILLY:** They might go to the clinic to get patched up or for some other reason. However, in my personal opinion, their own beliefs are stronger. That would vary according to how much contact people had. I do not pretend to know much about the day to day life of Aboriginal people in Alice Springs. I do not have the contact that I had when I lived out bush.

**Mr RIOLI:** Debbie, you mentioned that people in the Kintore community had asked for their old and sick people to be sent to Alice Springs to be treated or for palliative care.

**Mrs BROWN:** At Old Timers, we have had experience with a number of elderly Aboriginal people. Arrangements have been made through the clinics and so forth for them to come in for a month of respite care and to give them a spell away from their usual carers. When the flying doctors bring them in, that is fine. However, when we go to send them home we find that the families have moved on. We are then left with an elderly Aboriginal person, not knowing what to do with them. They often end up in the Alice Springs hospital because their primary carers have left. The flying doctor has no resort but to bring them back and they go into Alice Springs Hospital until somebody can find the family.

I do not know if that applies to all Aboriginal people or just Aboriginal people from certain areas. However, we have had people from Utopia, Kintore, Halls Creek and a variety of places. As I understand it, the death of an elderly person in an Aboriginal community has considerable repercussions and the community may prefer it not to happen.

An Aboriginal gentleman called Robert I cannot remember his last name came out to talk to us about cross-cultural issues. He said that, in the Aboriginal community, they virtually practised a Natural Death Act. When a person was close to death or too aged to keep up with their people, or their people did not want to care for them, they put them in a nice place in the bush with some food and water. This is as he said it. They put them under a shady tree in a comfortable position, and left them. That is the same as removing all extraordinary circumstances of care. They allowed nature to take its course. They do not actively practice euthanasia but they actively take them out of the community and put them somewhere to die alone. He is an Aboriginal man. Maybe there are a lot of differences in the Aboriginal communities and what they prefer to do.

**Mr POOLE:** We asked them that very question and they put it down to stories.

**Mr RIOLI:** Was Robert from Alice Springs?

---

**Mrs BROWN:** Robert is actually a linguist who is putting various Aboriginal languages down on paper. The government employs him to do that and to do crosscultural sessions.

**Mrs BRAHAM:** Debbie, is that Robert Hoogenraad, working out of IAD?

**Mrs BROWN:** Yes. I think that is him.

**Mrs BROWN:** He is German.

**Mr RIOLI:** He is German?

**Mrs BROWN:** He works with Anna Franks.

**Mr POOLE:** Yes.

**Mrs BROWN:** He seemed to be widely travelled and had gained a lot of his information from various areas. I think he is from Darwin originally.

**Mr POOLE:** Yes.

**Mr DUFFY:** Just on the question of the boundaries, Maurice, the Alice Springs parish is not just the town. We meet the Tennant Creek parish up the track. There is a parish associated with Santa Teresa. We have a boundary there. We go out to some sort of parish in Western Australia and we also go down south. Yulara is serviced by a South Australian diocese, not from Alice Springs. I think our boundary is around Imanpa or somewhere around there. So a number of Aboriginal communities are within the boundaries of the parish.

**Mrs REILLY:** I would just like to offer something else in terms of Aboriginal experience although it relates to the question of blame for death rather than to palliative care. I know of some instances in which patients have been sent to hospital in Adelaide, including younger patients who may have suffered an accident or whatever and are in need of acute care and whose family members are with them. In one such instance, a young man died. His relations subsequently blamed his wife for the death.

Again, it is a problem of communication and the lack of understanding. Medical practitioners might perceive that such a young person needs certain highly technical procedures or operations to maintain his life. There is a whole family communication network which has to be consulted in order to reach agreement about what is happening. That process takes time which western medicine does not always allow for. The family repercussions can go on for years. Maurice, you would know what I am talking about. There are 2 different worldviews. It is a very hairy situation. I do not know how you even begin to embark upon it in terms of traditional Aboriginal people.

**Mr POOLE:** Yes, I think we have identified that as another grey area to be further discussed.

---

All right, are there any further questions? If not, we thank you very much. We really appreciate the time that you have devoted to developing your submission and presenting it at this late hour. It has been very interesting.

**Mr DUFFY:** Thanks very much for giving us the time. I know we allowed for a lot less time and we are very appreciative of the fact that we could get this amount.

**Mr POOLE:** Thank you.

**Mr DUFFY:** I will leave you that corrected version.

**MR RIOLI:** That was a German fellow, you were saying.

**Mrs BRAHAM:** Robert Hoogenraad.

**Mr POOLE:** He has been a German. Officially.

**Mrs BRAHAM:** Yes.

select COMMITTEE **ON EUTHANASIA**

**TENNANT CREEK**

**PUBLIC HEARINGS**

Tuesday 4 April 1995 Opened: 11.05 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Mr T C Tate

**Note:** This is an edited transcript.

**Issued: Tuesday 18 April 1995**

---

**Mr POOLE:** I declare open this meeting of the Select Committee on Euthanasia on Tuesday 4 April 1995, and welcome Mr T C Tate, who is appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise you that the committee has authorised, for the purposes of this inquiry, that the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Please advise us now if that is the case. In other words, do you wish your evidence to be confidential?

**Mr TATE:** No.

**Mr POOLE:** For the Hansard record, please state your full name and the capacity in which you appear today. We are recording, and these are the microphones.

**Mr TATE:** My name is Max Charles Tate and I am a simple man off the street having my say for the case of the affirmative for euthanasia.

**Mr POOLE:** In the public hearings we have been allowing people to say what they want to say and then, if you are willing, we go into a questionandanswer situation, all right? We have allowed up to about 45 minutes; if we need to extend, we can.

**Mr TATE:** This will take 5 minutes. Good morning, ladies and gentlemen. Please bear with me as I have never spoken in public before. I believe this issue is so important that even a shy son of a pig farmer has to pop out of the crowd and be heard. Personally, I would rather talk about any subject but euthanasia astronomy, religion, autoelectrics, gyrocopters, the paranormal, sex ... Who likes talking about death? Talking about life is much better. However, we must all face death one day, so let us get used to it.

Actually, I have been interested in euthanasia for a long time. Usually I ask someone who has been stuck in a car with me for a few hours, and we have run out of naughty jokes: 'What do you think of euthanasia?' They often reply: 'I don't know, what do you think?' I then realise they do not even know what the word means.

I wish to represent a large percentage of ordinary Joe Bloggses like myself, who are given a right to life, which we appreciate, but not a right to death. We are not asking for a right to death any time, but a right to die in dignity when the quality of life has gone and all that remains is suffering and eventual death, which causes hardship not only to the patient but also to his or her loved ones.

To keep someone alive when they wish to die, in my opinion, is a form of institutionalised torture. A dog has more rights in this area than a human. Euthanasia, I believe, is an act of love when applied to a willing patient who is suffering and dying. I realise that many people are blinded by religious influence, but I believe that euthanasia will be legalised one day, so let us look forward to a humane future instead of backward into a superstitious past.

I have discussed the subject with many people in the field and have found that most agree with euthanasia but are unwilling to speak publicly. When I say in the field, I mean nurses, for example, who deal directly with dying patients. Sure, let us make it compulsory to get lots of signatures from lots of experts before someone is allowed to be terminated, if you excuse the word. Most times, it is only the technology that is keeping that person alive anyway. If they were in the last century, they would die anyway.

I am not going to talk of my own personal experiences on this subject, and use emotion to get my point across. I know I shall be branded after taking this stance as Mr Death, but sometimes a Mr Death can be an angel in disguise.

Many people take their own lives anyway, if they are capable. I believe euthanasia will drop the suicide statistics, save billions of dollars in medical costs, and satisfy countless patients who can pass on with dignity at their own request.

Of course, we should not kill ourselves as soon as we are in pain. I agree that euthanasia should not be too easy to come by. I was in so much pain the other day, after making a guts of myself on a 'Slush Puppy', that if I had had a revolver handy, I would have shot myself. Three minutes later when my brain warmed up, I was okay.

When I say euthanasia, I do not mean shutting off life support. I mean administering a fatal drug which allows the patient to slip away peacefully.

To finish off, what I would like to say is when I took my dog to the vet the other day to be terminated, I remember thinking if only we humans were allowed to die that peacefully, we would be a step closer to a beautiful world. Thank you.

**Mr POOLE:** Thank you. We might just move some of the chairs up a bit so that people can actually hear. Questions?

**Mrs BRAHAM:** Max, have you read the bill?

**Mr TATE:** No, I have not.

**Mrs BRAHAM:** Would you have any concerns if euthanasia was given the right? You have said you are very much in support of it, but is there any side of the bill that may cause you concern?

**Mr TATE:** Not if it is executed properly. As I said, I have not read the bill, so I cannot really accurately answer the question.

**Mrs BRAHAM:** But you have no feelings at all that it could be mismanaged, or could be done incorrectly, so that it becomes involuntary euthanasia rather than voluntary?

**Mr TATE:** No, I believe that is just a scare tactic used by the people against euthanasia. I believe that the people concerned will be mature enough to make the right decisions.

**Mrs BRAHAM:** You obviously have confidence in the medical profession to make sure that it is not abused, and it is done correctly?

**Mr TATE:** Definitely, yes.

**Mr STIRLING:** That point you made about the quality of life, that you did not think it ought to be accessed as a normal right, but at a point when the quality of life was such that the person might want to die. I guess that is a subjective sort of area and people have their own views on what 'quality of life' actually means. Could you elaborate on how you see that?

**Mr TATE:** In a terminal illness case, where you are going to linger on. You know you are going to go, and you might as well go in dignity at the time you choose, rather than hanging on there.

**Mr POOLE:** The bill actually has a timeframe attached to it. It is basically when a medical practitioner says that you are not going to live for longer than 12 months, and that view is supported by a second practitioner, who also talks to the patient and agrees with the original diagnosis of the illness and, of course, agrees that the patient is volunteering to end their life.

**Mr TATE:** Yes, I have heard that statement and that is what I agree with.

**Mr POOLE:** Okay, any further questions? No, all right. Thank you very much.

select COMMITTEE **ON EUTHANASIA**

**TENNANT CREEK**

**PUBLIC HEARINGS**

Tuesday 4 April 1995 Opened: 11.15 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Moore (Nurse)

**Note:** This is an edited transcript.

**Issued: Wednesday 19 April 1995**

---

**Mr POOLE:** I think you were here at the start of the session?

**Ms MOORE:** Yes.

**Mr POOLE:** Basically, while we do not require you to take an oath or make an affirmation, and I appreciate that what you are expressing is a personal view, if you quote any statistics or anything like that, the information must be truthful.

Any evidence that is given to the committee normally can be published. If you have a difficulty with that, you can request that your submission be made confidential. Would you like it to be open or confidential?

**Ms MOORE:** Open.

**Mr POOLE:** Okay, fine. Again, what we have been doing basically is allowing people to speak either to their submission that they have already given us, or make their submission, or give us their thoughts. Then members of the committee can ask you questions. All right?

**Ms MOORE:** Yes.

**Mr POOLE:** Over to you. Please state your full name and the capacity in which you appear.

**Ms MOORE:** My name is Wendy Florence Moore. I am a triplecertificate nurse. I have been in a third world country for 20 years, in community health work. I have been a village worker as well as setting up motherandchild clinics. My work was particularly that, but of course I was everything in the village, because I was the only medical person. I have had firsthand experience of many people dying, as you probably realise, including in my own family.

All my life as a nurse, I have not ever believed that anyone should have the power to terminate anyone else's life. But I have watched many suffer and I do believe in relieving pain. I do believe in the care that is taken for that also, and the responsibility to tell the families and for them to understand.

I have had many experiences, so I could not name them all. I did have an uncle who was dying of cancer. That was a very devastating thing for our whole family. I had not known that uncle very long in a way of being close to him. I only really met him as a person when he was ill. I was very interested to know how he was being looked after, because he was a returned serviceman.

At first he did not know he was terminally ill. He went into hospital with an ulcer problem, and when he had the operation they discovered that he had this cancer. The doctor performed a 7hour operation but said my uncle might not pull through overnight. He was not

---

given any hope of having any further life, but he was still very much aware of what he was doing. Never at any point did I think of suggesting that he could terminate his life. I realised that his suffering could be reduced by the medication that he was given.

He lived 7 weeks. I do not have any regret. I did not feel that was terrible. I got to know him, and to know his religious beliefs, as well as coming to a point where I realised that I had never thought of thanking him for coming back from the war with his injuries. As children we prayed for him. When he came back, I was devastated because he was an alcoholic. He went from the family and we did not see him.

When I came to this point of knowing him, I learned all about his life. That time was very precious. I said to the doctor: 'He has lived for 7 weeks. In that time I have come to know him, and in that time he has told me how he has come to know the Lord. I had time to thank him for what he did in the war'. That opened the floodgates for him. Nobody of the family had ever ... they loved him, but they did not know what to do for him because he was an alcoholic all his life, and he was away. So I would never ever consider, although he was in a shocking condition ... At the end we were all around his bed, and he died in the night.

**Mr POOLE:** Did he ask at all for help to pass on?

**Ms MOORE:** No, he did not. Well, not to my knowledge. He could hardly speak.

**Mr POOLE:** So even if the law had permitted it, you do not think he would have taken advantage of the law anyway?

**Ms MOORE:** No, I do not think so. He had been through a lot in the war. He had been through all of the Middle East. He was only 17 when he went. He was not old enough, really, to go. His mother died when he was 3 months old, and he was in an orphanage until he went to the war. He came back without a family of his own and did not ever have a family. And yet, through his life, I discovered that he was very aware that God had cared for him all that time.

The family had prayed also. But we were Anglicans and we never discussed any religious things. It was only the time when I was there. I am amazed that only just recently, hearing about the war, it came to my mind that I had never thanked him for going there for me. Nobody else had ever thanked him, either. So that, to me, was a precious thing.

But then, my mother had a little dog who was with her for 13 years. She had done everything for that dog and spent a lot of money, but it was worth it because he was her companion. We were really happy, because Alfie was always there. When the phone rang and she could not hear it, he would talk to her, tell her it was ringing. Then just recently he was ill he had had an operation before and while I was not there Mum took him to the vet. She came home with the dog in her arms and said: 'The vet's put him down and he could have had an IV, you know'. The vet had said: 'He has cataracts and is going to go blind. He really looks like he's just about on the way out. So I really don't think that I could give him an IV. I think I'd put him down'.

---

Well, my mother is still grieving over that. She said: 'You know, if you had been with me we could have taken him home'. Perhaps he would have died in the night, but she has her own thoughts. She said: 'He was my companion and what did I do to him?'

People think about it later on, you know. They ask opinions of people in positions of authority. Of course, we consider the doctor the one to advise us, but I think that when you look behind all the relationships of families, sometimes you are not really seeking the advice that may be given. I do not consider that I could ever consent to this type of bill.

**Mr POOLE:** One of the facts with regard to the bill, of course, is that it does not rely on anybody else apart from the individual concerned. The individual has to request the doctor to take advantage of the act. So the analogy of somebody else making a decision for you is not there. But I appreciate that if it involves a close one, and the husband or the wife discusses it yes, I can see the problem. I think we have already had a bit of evidence that the time, what I call 'the cleansing of the soul period', is very important for people who are terminally ill, and probably even more important for the family around them, to give them a chance to discuss and clear the air on family matters.

**Ms MOORE:** I intervened unwittingly when I went to Nepal. In the village there, I found an old woman put out in the yard. She was not even under an awning. I said: 'What's happened? She's so dry she hasn't had anything to drink. At least put her under a shade'. They said: 'She's ready to die', and she said she was, too. I was responsible in the village, so I said: 'Put her under an awning', and gave her a drink. They did not stop me, because I had been there for a long time. Then gradually we brought her back onto the verandah, just to be on a clean surface to die. We took food to her but she would not eat it. She gave it to her little grand-daughter because she needed it more. We found clean things for her and washed her up and arranged a place where she could go to the toilet. We looked after her for a whole week. Just before she died, she asked: 'Will I have a nice pillow like this in heaven?'

She was old and she was ready to die. In their tradition she would have died out there within a few hours. To me that was an opportunity for them to see that you can die with dignity and that there was a need met. They were also, as a family, much closer together. The only thing was that I had to back off then, because they believed that the spirit had to be released outside not within the house. I learned what they were on about and they learned what we were on about, and we shared both ways.

**Mr POOLE:** What about in the case of somebody that is suffering a terminal illness that is extremely painful? While I think everybody acknowledges you can manage pain pretty successfully nowadays with the drugs that are available, there will always be a percentage, albeit a very small percentage, of people for whom you can really do nothing, or you can only dose them up to such a point. The pain continues to override the drugs they have been given and they are saying: 'Look, put me out of my misery. There's no hope. I want to die, and I want to die without going through all this tremendous pain'.

---

**Ms MOORE:** I have had to face that in my nursing, where the medication is there and the doses have been given, but I have never come to the point where it has been like an overdose to give. Whenever I went to see my uncle I was a bit devastated because they gave him a large amount of morphine before I got there and he was asleep for my benefit. I said: 'You know, it should be for his benefit'. I was glad that he was relieved of pain, but I would stay there and wait until he was able to know that I had been there.

I hesitate. As a Christian and I have a very close relationship with the Lord and knowing the dignity of man, I have even prayed to the Lord: 'Take them now', and he has, as if he has closed their eyes and they have died. But I never want to leave a person without hope.

Once a woman walked for 5 days to bring her child into hospital. Looking at her and the baby, it seemed to me that the mother's will had kept the baby alive. I called in the doctor, who said the child was too far gone. 'You do what you can', he told me, because I was in charge of that part, 'but it's too far gone'. He did not use their language, but as soon as that mother saw his face as he was saying, 'too far gone', the mother closed the little eyes like that and the baby died.

**Mrs BRAHAM:** Can you tell us a little about the situation in Tennant? Do you have cases of the elderly dying within Tennant Creek Hospital?

**Ms MOORE:** This is not the hospital, but the nursing home.

**Mrs BRAHAM:** And are there any cases where people who really are at the terminal stage request help?

**Ms MOORE:** There has never been anyone to request help for dying that I have known about. Some family members have requested help to a stage that made me feel that there is a certain limit to which you can go. I do not believe in limiting life. You do as much as you can, but it is up to the family to be with them.

When a life is prolonged like that, the family should be with the person as long as they can stay. What is devastating to me is seeing them moving away from the person who is ill, with the attitude, you know, 'They don't really know what's going on we'll only stay for a few minutes'. I feel sometimes, if only you could just sit and hold their hand and talk to them about family. It does not matter whether they can hear you or not. This moving away even doctors do it. They have done all they can and they feel so devastated about it. I have heard patients plead that people not move away from them, not give up on them. And sometimes I feel that this business of euthanasia is a giving up.

**Mr POOLE:** We have been told, and there has been comment in the media, that in some cases doctors administer drugs to the point whereby they overdose the person to the extreme, not with the idea of killing them I am not implying that anybody does that but purely for the management of their pain. The effect, the byproduct, is that the patient quite

---

likely dies or there is a strong possibility that they will die. The argument is that the paramount thing is the intent the intent not being to kill the person, the intent being to manage their pain, give them and offer them some relief. Have you ever experienced that in the years you have been practising medicine?

**Ms MOORE:** Yes. This is a recent case, not involving me but good friends living across from my mother's house. The lady's husband was obviously in great distress and dying. The wife had done all she could at home, and they took him to hospital. He had said to her: 'You know I can do nothing more for you'. I did not express my opinion to her. I just listened, because still in my heart I have my own thoughts about that. But I did not feel that it was wrong for the doctor, either, because the doctor listened to him. He said: 'Frank just said goodbye to me and said not to worry about him'. The doctor gave him an injection, and he went to sleep and did not wake up. He was in such distress with his breathing that he would only need to go to ordinary sleep and I do not think that he would have woken up.

**Mr POOLE:** But in effect that is euthanasia, is it not?

**Ms MOORE:** Yes, but I am giving my opinion for the first time. I never expressed that to her. I thought: 'Let her work that out if she wants to herself, or understand it'. Her husband had given her understanding.

**Mr POOLE:** What this bill is proposing is very similar, I think, to what you have just described It decriminalises an act that probably occurs throughout the country now according to statistics, anyway.

**Ms MOORE:** Well, I do not know. Law is a funny thing. When people come up front with it, as these doctors have, they feel threatened that they are going to be liable for what they have done in the past. The law certainly is not going to save them in cases that will still come forward.

**Mr POOLE:** Is that in itself not a contradiction? I am not saying that I condone anybody doing anything illegal, but it is apparent that there are sections of the community tolerating people being put down, either by doctors themselves or by families. Yet it is illegal.

**Ms MOORE:** Yes, but this I do not agree with, because this is saying: 'Now, you have 12 months to live'. It does not say in this that the person could have palliative care. And I know of people who have been given 12 months to live and they are still living 7, 8 years later. I know personally of those, and I have listened to all the things on the radio. One woman who has gone through shocking things said: 'Even if you say that I've had a terrible life, I would never ever say that I wouldn't have wanted to go through this time.' She said she had learnt so much about herself and about coming to terms with her own family. To have somebody say that at the end of it ... Because this is a sentence on you. You have it in the back of your mind that you have committed yourself to something. Is it reversible?

**Mr POOLE:** Well, it is ...

---

**Ms MOORE:** But is it, really?

**Mr POOLE:** Well, according to the bill there is a clause that at any time you may refuse assent and just say: 'Look, I've changed my mind'.

**Ms MOORE:** But you always have it in your mind that this is expected of you. 'Is this my decision? Am I making my family suffer? Will it be better if I go?' This is human nature, that people want to do the best for their families. I have seen people who are absolutely at their life's end, and for their family, when they come in, they put on the best face they can because the family are too pained to see them in this condition. I have even heard them say: 'I've got no one that will come close to me at this time, that will put their hand on me and say that it's all right to have this pain'.

**Mr POOLE:** What about the case of doctors doing it to people who do not ask for it? The pain, and I guess the pressures of the family, and the doctor's own professional instincts are such that he or she says: 'This person shouldn't be suffering the way they are, so I'm going to give them an injection' again, not with the intention of causing death, but to manage pain without actually saying to the patient: 'I'm giving you an injection. You might not survive it'.

**Ms MOORE:** I think that is absolutely the worst thing that could ever happen.

**Mr POOLE:** But apparently it is happening.

**Ms MOORE:** Yes, but of course in human nature, we can all make mistakes. As a nurse, what you are trained in can be a mistake. For example, mothers can go and visit their babies and be in hospital with them. When I started nursing, there was only a restricted time for visiting. I personally sat with a little child that cried for its father all night. Because he was a farmer and could not come at that certain time, he had never come in to see him. Everybody felt it was righteous because the children might be upset or the routine would be disturbed, and you go along with that. But that particular night I thought: 'What are we doing? We are gatekeeping!' If you are going to accept the responsibility and ...

**Mr POOLE:** Some would put the argument, of course, that it is better to have it all above the table, so we know exactly how many people it is being done to ...

**Ms MOORE:** That is true. It is good that it comes out.

**Mr POOLE:** ... and do not have doctors playing God.

**Ms MOORE:** This is what this debate is for, is it not? Ordinary people do not know what they really think until they start talking themselves, and understanding. Actually, I had only just read that. I asked another person: 'Did you realise what that was?' If that was the case, they said, they would not have anything to do with it either.

---

**Mr STIRLING:** Wendy, early on you made a point about the doctor. I read into it that people tend to see the doctor as the expert or the all-wise, all-knowing, and may well seek their advice on these sorts of things. Did you think there was a problem with that?

**Ms MOORE:** I do not think there is the problem that there would have been, because people are no longer putting the doctor in that category. There are the rights that come up as the patient's rights to know. When my uncle was dying, I thought the doctor was saying too much to him, because he was just coming into the hospital with a heart attack. That doctor had the right to tell him what was happening to him, what medication he was given, and he looked at me as much as to say: 'What do I have to do about this?'. He had just come into hospital and he really was not with it to understand what he was told.

I think it depends on how long you have been a doctor, too. You can get an understanding of what are the rights and how you put them forward. Some doctors take the view that if they set it all out, now the patient knows, and then you can get on with the business of where you are at next. Am I answering your question, or am I putting another complex thing? I explained to my uncle: 'That's the way they tell you these days. The doctor's just letting you know'. And then I thought, getting on to relieve the pain was what he was concerned about at that stage, and knowing that he was going to be comfortable in bed for a while.

**Ms STIRLING:** In all those years in third world countries, you must have had a number of cases of people desperately ill and close to dying. Without western hospitals and things to assist, you never thought at any time yourself that you wished there was more you could do for that person to end their suffering?

**Ms MOORE:** No. There are a lot of religious things, all done at home. The religious connotations came first, the hospital last. The doctor had to give something on the spot, and they would say: 'All right, we're ready to go home'. That was their wish. Sometimes, of course, you would wish that they would stay longer. Sometimes they would come back and say: 'That medicine worked. Will you give us some more?' But they do not send their people off to hospital when they are dying. People stay with their people all the time, throughout the night and throughout the day. We think it cannot be done here, because it is just too much. In third world countries, that is how things are. Nobody is going to say to them: 'Now you have let somebody die'.

When my father died, before I got home, he was taken to the morgue because his own doctor had not seen him. The other doctor had to write out that this was a coroner's case because he did not know the person or his history. Well, 2 hours later when I got home the police had come and taken him away. Here was my mother sitting on her own. That was a devastating experience, also for me. I did not think that it was bad. I understood the reason behind it all and I had been brought up to that. But when I go to a third world country, I start thinking more about the dignity of people. The doctor that had to see to my father was the medical superintendent of the hospital that I used to work for, and a very dear friend. He had been out that night. When he was told about it he said: 'Oh well, if they bring him in now, I'll be able to see him'. I did not ever tell my mother anything about that.

**Dr LIM:** Wendy, you know, as a very senior nurse with your extensive experience probably more than a lot of us younger doctors with the treatment of patients a moment comes when you cannot do any more. What do you do then?

**Ms MOORE**: Then leave it to God. Leave it to God. I mean to say, this is what the doctors are doing. They feel so devastated. I have seen doctors absolutely cry over their patients. I know the pain they go through. I know a doctor who helped many women to go through their pregnancies and have beautiful babies. He had gone in for a delivery but the baby did not breathe. He had done absolutely everything in his power. To have to go in and tell that mother ... He could not face it. He had to ask the nurse if he could come back later. Sometimes we would say: 'We'll give you a cup of tea, doctor, and then you go in and see her'. Even doctors who have known that they should go and confront them sometimes cannot. They get so emotionally involved. I do not believe that any doctor can ever not be emotionally involved in those situations. But when you are wanting to do more, there is a point where you are not God.

**Dr LIM:** Do you think at that stage, though, that ...

**Ms MOORE:** Your responsibility should be handed over to a higher power.

**Dr LIM:** Well, do you think that might be abrogating the responsibility that the patient still needs your help ...

**Ms MOORE:** Of course. Do not withdraw from the patient, that is what I say. Do not withdraw. Put your hand out and just hold them, and say: 'I'm near'. Some doctors forget. Some, especially Australians, are not touching types. Nurses can help in that situation, too. I have often said: 'Doctor, there's somebody been just so waiting for your word', and been told: 'I can't do anything more and I don't really know what to say to her. What can I say?' I reply: 'Well, just go in and hold that hand'. A doctor I knew in Nepal used to put his stethoscope on everyone who came in and he did not have it in his ears! This was just public ...

**Dr LIM:** It is the laying on of the hands, that is what it is.

**Ms MOORE:** ... and they just thought he was wonderful. He did not speak Nepali he spoke Hindi but a lot of people understood. He would say 'We are only the shepherds, only the minders. We are His workers and we are only in His hands'. And he did miracles. He was a miracle himself. He was on 2 crutches and he walked up a mountain that my mission secretary never made, and he operated.

**Mr POOLE:** All right, any further questions? Thank you very much, very interesting.

select COMMITTEE **ON EUTHANASIA**

**TENNANT CREEK**

**PUBLIC HEARINGS**

Tuesday 4 April 1995 Opened: 12.00 noon

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives: Full Gospel Business Men's Fellowship International

Mr Richard Cherry

Mr Rod Geri

**Note:** This is an edited transcript.

**Issued: Friday 21 April 1995**

1

---

**Mr POOLE:** I declare open this hearing of the Select Committee on Euthanasia and welcome the following witnesses on behalf of the Full Gospel Businessmen's Fellowship International, Mr Richard Cherry and Mr Rod Geri.

Other than in exceptional circumstances, witnesses appearing before the committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful.

I also advise that the committee has authorised, for the purposes of this inquiry, that the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right, however, to request that their evidence be taken in camera and/or remain confidential. Please advise now if that is the case.

**Mr CHERRY:** It is completely open.

**Mr GERI:** Yes.

**Mr POOLE:** For the Hansard record, please state your full names and the capacity in which you appear today.

**Mr CHERRY:** My name is Richard Peter George Cherry. I appear as a member of the Full Gospel Businessmen's Fellowship International, Tennant Creek.

**Mr GERI:** My name is Rodney Craig Geri. I appear on behalf of the Full Gospel Businessmen's Fellowship International, Tennant Creek.

**Mr POOLE:** Thank you. You have seen how we go about our business. We allow you to talk to your submission and at the end of that period, we can go into a questionandanswer situation. All right? Over to you, gentlemen.

**Mr GERI:** There are 2 parts to our presentation. I shall briefly go over our proposal, and Richard will follow on with the finer points.

Please receive this submission from the Full Gospel Businessmen's Fellowship International, Tennant Creek chapter. The proposed bill that the select committee is considering is intended to legalise the option of assisted suicide as the right of a sane, adult person suffering from a terminal, painful illness, who has been diagnosed as having a life expectancy of 12 months or less. Underpinning this bill are ethical and moral views which, though related to religious thinking, are also related to a number of human rights in general.

Prior to outlining 5 such notions, I wish to affirm that as Christians, euthanasia is incompatible with our understanding of the gospel of our Lord Jesus Christ, and the sanctity of life as revealed through the Bible, which we accept as the word of God.

2

---

The 1991 census clearly indicates that a clear majority of Territorians claim a Christian heritage, which will vary among people as illustrated by the different denominations. However, all Christians hold that there will be a resurrection, and that all people will be accountable for their own decisions and all their own actions.

However, we also contend that in terms of the moral and ethical traditions of our society, to propose terminating a human life by medical practitioners creates serious problems in terms of human rights. These problems are outlined in the 5 following statements.

**Mr CHERRY:** Did you want us to continue, or would you like to raise questions?

**Mr POOLE:** No, we will leave the questions until we get to the end, if you like.

**Mr CHERRY:** We are talking about notions here, not specifically the text of the bill.

1. The proposed bill claims that the value of life and the quality of life are the same thing. That is, anybody having a serious

disability is seriously diminished in value, such as a person who is in the last part of their life suffering from a serious terminal illness. Such a rationale is contrary to our society's current rejection of suicide as a human right for those dissatisfied with an earthly existence, because most people who commit suicide are at the time in a state of great distress, anxiety and often extreme mental pain, as in the case of serious clinical depression;

2. It assumes suffering devalues life, and in so doing denies the moral traditional of triumphing over, though not necessarily surviving, adversity. I think all of us know examples of that. There are the rare exceptions, of course, and a very well noted rare exception is a person called Stephen Hawking, who has been debilitated a number of times and has lived for 30 years longer than, I think, the doctor initially expected him to live.

3. It contends true compassion is to alleviate suffering of a dying person by hastening death, not by providing love and care and support. It denies the worth of the historical tradition of Australian soldiers, injured throughout this century, where we have responded to them with repatriation and hospitalisation. I say that particularly in the case where many of those soldiers have been shattered, have come back and have actually died perhaps within a month or 2 months or 6 months or 2 years or 3 years after they have been returned. They have been looked after in that process.

4. As a consequence of this bill, the importance of palliative care is diminished for the civilian population. I think in a similar way, as we have heard many people argue, people who are expected perhaps to take an injection would take an injection, rather than linger on for months or years in a very dependent situation. Mankind is equated with other animals, which when suffering seriously are frequently put down. In so doing, the bill denies the metaphysical personhood of humans. Metaphysical personhood is recognised in many cultures throughout the world which are not founded on atheism, not least of which is the Aboriginal community in many ways, if one takes a very broad view of the concept of metaphysical personhood and thinks in the traditional way of the Aboriginal culture or religion.

5. In presuming that euthanasia can be tightly controlled, the bill is in error, as delineated by the Right to Life News, incorporating Life Letter, special euthanasia supplement, March 1995. This supplement documents the range of international citations and abuses of euthanasia. In so doing, it draws our attention to problems in maintaining moral integrity which so frequently befall mankind. I bring that to you as a very important factor. I have documentary evidence from the director of the Southern Cross Bioethics Institute in Adelaide, South Australia, Rev. John Fleming, on the Netherlands in 1990. Perhaps that paper has been presented to you and you have heard evidence on that already. It is referred to in brief in the newsletter I referred to.

In conclusion, we urge the select committee to note the serious deficiencies in palliative care in the Northern Territory, and urge that positive recommendations are made to address this deficiency in medical care. May God's providence lead you to the right recommendations. Yours sincerely and it is signed by Jim Phillips, our president, who cannot be here today, Rod Geri, myself Richard Cherry, and Ian Field, who is currently on holidays and unable to attend. We thank you for hearing our submission and we are only too pleased to answer any questions in relation to it.

**Mr POOLE:** Thank you. In effect you are saying that you and the group you represent believe the sanctity of human life is such that euthanasia should not even be contemplated as far as the law of the land is concerned?

**Mr CHERRY:** As Christians who have a faith in God and the Bible as the revealed word of God, we hold to that. At the same time, as you have drawn attention to it, there are obviously occasions when a doctor is making a decision between active and passive euthanasia, where a doctor must make a decision about treatment and care. I think that applies even if you happen to be a nursing sister, or a even a person helping a person. I have done a first aid course, and have been taught to resuscitate people according to the St John Ambulance formula. Now how long do you continue to resuscitate a person when their vital signs are not showing? We do know of people who have been given resuscitation for 20 minutes and have recovered, but that is not always apparent. People have to make some decision in that respect.

**Mrs BRAHAM:** You argue from a religious point of view, saying that we are a Christian population and we believe in the sanctity of life. You strongly believe from this religious point of view that this bill is unacceptable to you. But would you agree that many Christians agree with the bill? We have had evidence from Catholics and other Christian people who are in support of the bill. If you accept that there are also many Christians who agree, do you think that you should really oppose or restrict this bill, which will give people the right of choice? Because you have a Christian belief that is against the bill, do you really think that as Christians, you should then deny others that right to choose?

**Mr CHERRY:** Perhaps we can both answer this. As a chapter, we hold to our doctrinal principles, which are the basis of the cohesion of the chapter. Those doctrinal principles do not exclude euthanasia as particular belief, but on our understanding of scripture, that happens to be the case. Rod might put it into slightly different words. We tend to hold to

---

a very faithful view that we trust in God to look after us in all adversity. We are going to die a physical death one day. Some people are going to die a very painful physical death; some people will die a very quiet physical death, perhaps in their sleep. Nobody would want to bring a painful physical death onto someone, but if that occurs, it is part and parcel of the existence of people. Actually to facilitate a person's death to stop a painful physical death, we regard as equivalent to murder.

**Mrs BRAHAM:** Would you respect another person's right to say: 'This is what I want'?

**Mr CHERRY:** We would hold let me put it in my own words I would hold that suicide was suicide. If a person decides to commit suicide, they commit suicide. But if a person assists someone in committing suicide, they are in some way involved in a homicide. Now, to what degree that is a murder will vary from case to case. But in some cases, where the patient is completely under the control of a medical practitioner and that practitioner instigates the person's death, then in our eyes that would be murder.

**Mr GERI:** I think Richard pretty well covered the points. Going back to the paragraph about people having a Christian heritage, I guess a lot is based on different Christians' understanding of the Bible and the word of God. Different people around the world who call themselves Christian come under a broad range of religions and backgrounds. But we as a chapter in Tennant Creek believe in the sanctity of life. We follow the word, what the word of God says on this teaching.

**Dr LIM:** Take an instance when you go to a doctor and he says: 'I cannot support euthanasia, but there are other ways you can do it'. Suppose doctors give you advice and explain methods and medication or drugs that you could use, and then you go ahead and decide to do it yourself, based on that information. Would you see that as acceptable?

**Mr CHERRY:** Could you say that again?

**Dr LIM:** If you have a doctor who provides the advice without participating in actually performing the euthanasia act for the patient, saying something like, 'This is what I would do, these are the drugs I can take', or, 'Go to Warrego and take some cyanide', or whatever, saying those sorts of things and giving the advice will not actually be part of the process.

**Mr CHERRY:** My own view I do not speak for the chapter in this regard is that that would be a dereliction of the doctor's responsibility. I imagine that if people wanted to do that, that is what they do when they commit suicide. They go and get a box of tablets and they do just that. If a person has a terminal illness, I imagine in most cases they could choose to do that for themselves, and it would be straight suicide.

**Dr LIM:** Except that they may not know the appropriate medication to use, and may come to a lot more harm than actually terminating their own life. They could semi-recover

---

from the overdose in a damaged state, a lot worse off than before they tried. Whereas, if they went to see somebody who could give them some proper and accurate advice, they might achieve the same end. How do you feel about that?

**Mr GERI:** I would like to know the depth to which the doctor counselled the patient before he came to that conclusion, and also the person's state of mind when he was going to take the medication from the doctor whether or not the person was in a stable state of mind. But basically I still do not agree with it, because it still disagrees with what we believe is the word of God, taking another's life. So basically, no. Personally once again, I do not believe that it is a course of treatment. As an ambulance officer that is my profession I have been to many cases where people have attempted to take their own life and things like that. I found in a large number of the cases that people were not in their right mind at this particular time. With counselling and with medication and things like that, I think they may take that course of action at the time. But when they are able to see the circumstances more clearly, I think they would have learnt that there was a way out.

**Mr POOLE:** What is your attitude to suicide in general? It has been decriminalised virtually all around Australia. It is still on the statute books in the Northern Territory, but virtually every other state has taken suicide off their list of crimes now. It is still, I believe, in most states against the law to help someone commit suicide, but the actual act of suicide itself is no longer a crime.

**Mr GERI:** I personally do not agree with it. Without looking at every individual case and the person's reasons, as a Christian and from my own ethical and moral standing, I do not believe in suicide. My own mother died of cancer years ago. The family rallied around and supported her at home. When she had 6 months to go the family pulled together as a unit and were able to give each other strength and encouragement to help mum die. So I guess we have a bit of a background with a family member dying of a terminal illness.

I have been to other people who have successfully gone through and taken their own life, and I have seen the effect on the family and the hopelessness of the whole situation. People wondering why it had to happen this way, why did the person take their own life. I think they also see it as a reflection on that person's relationship with them. I guess a lot of people think that maybe the person who took their life at that time was not considering the other people whose lives were going to be affected.

**Mr POOLE:** Marshall Perron in his second reading speech said that in our society, while I do not think anybody stands up and supports the concept of suicide, there is the opportunity for normal people to go out and commit suicide in a multitude of ways, but other people who are terminally ill and are bedridden are just not in a position to assist themselves to die, despite the fact that they might be suffering fairly traumatic pain, etc. One of the ideas of his bill was to give them that opportunity. Is it right that one side of society can basically have that choice and the other side of society cannot?

6

---

**Mr CHERRY:** We would come back on our concluding remarks in relation to palliative care. The nursing sister who gave evidence earlier, Wendy Moore, can talk about the nursing home here in Tennant Creek, where there is a lady of 105 years of age, I believe. That lady is looked after like many elderly people, yet is at the same time, in many ways, not functioning as a human being, as we would take for granted. That is true of many elderly people, whether or not they are defined as terminally ill officially. In the sense that they may be highly restricted to a bed, very inactive, not able to do very much for themselves, needing assistance in being fed, not able to talk very much or if they can, have limited conversation. Those same people can, if given the right support I would suggest, be more active or interactive. But that requires programs of assistance which I think in many cases are currently lacking here.

**Mr POOLE:** But in an ideal world, say we had the best palliative care possible in all centres in the Northern Territory, and we were really looking after everybody to the utmost extreme that the medical profession and government can, and you had all the family support etc., you still, from what you are saying, would not accept the fact that certain people should have the right to say: 'Please, let me go'.

**Mr CHERRY:** As Christians, you see, we have faith in God. We would regard that dying process as having been according to God's will. But those people should be given attention. An example of a person known throughout the world for giving it is Mother Sr Teresa, who has gone to third world countries and endeavoured to give people on the street such attention. Now that is limited. It cannot be for everybody. But our view at least my own way of seeing it is that we should endeavour to give that care to all people.

You would say: 'What about those who cannot receive that care?' My view is that murder is murder, and that to ask a medical practitioner to end a person's life is asking them to take on a role equivalent to that of a murderer. Now, I appreciate that there is a difference between passive and active euthanasia. I think I have made that point.

**Mr STIRLING:** On your last paragraph, asking the committee to note the serious deficiencies of palliative care, I assure you that the report will stress the concerns that have been put before the committee at every one of its hearings in relation to the deficiencies. The Chief Minister himself has recently made quite strong sounds about addressing the needs.

**Mr POOLE:** All right, any other questions? Well, I thank you very much for the time you have given us this morning. Very interesting, thank you.

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 11.30 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Mr I M Hillock

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** Ladies and gentlemen, I call to order this hearing of the Select Committee on Euthanasia in Katherine on Wednesday, 5 April 1995 and I welcome Mr I. M. Hillock, who is appearing before the committee as a witness.

Other than in exceptional circumstances, witnesses appearing before the committee are not required to take an oath or make an affirmation. However, I remind you that any information you give to the committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do however have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us if that is the case. Do you wish it to remain confidential or are you happy to put it on the public record?

**Mr HILLOCK:** There is no problem there.

**Mr POOLE:** Thank you. For the Hansard record, could I ask you to state your full name and the capacity in which you appear today.

**Mr HILLOCK:** My name is Ian Mackintosh Hillock. I am appearing on my own behalf.

**Mr POOLE:** Mr Hillock, the format we have used in other public hearings is basically to allow witnesses to first speak to their submissions. If you want to read out or comment on your submission, or offer further information, that is entirely up to you. We have allowed 45 minutes for you to give evidence. We would ask you to confine your initial remarks to 30 minutes so that we have time to ask questions at the end. Over to you.

**Mr HILLOCK:** I think you have all received copies of my submission. I could read it out. I will leave that up to the committee. In addition to the original submission, I have prepared an appendix. The original submission was done specifically to refute arguments in favour of the bill. The appendix deals with particulars of the bill itself in reference to the stated intention for strict control and limitation by incorporation of adequate safeguards. I draw the committee's attention to certain clauses which, if enacted, would tend to negate the specific intent and in my opinion are more likely to promote general licence.

That was my view on reading the draft of the bill. I am not a lawyer and I therefore compared my notes with some legal opinions. By and large, those opinions were in agreement with my views. I have prepared an appendix which outlines certain qualities which, I believe, could negate the stated intention for strict control and promote general licence. Lawyers could have a field day with some provisions of the bill and could argue in court for ever. Shall I go through them clause by clause?

**Mr POOLE:** If you wish, yes.

**Mr HILLOCK:** Clause 3 states that:

---

*A patient of a medical practitioner who has been informed by that medical practitioner that he or she is suffering from a terminal illness and within reasonable medical judgment is likely to die within 12 months as a result of the illness, may request the medical practitioner to assist the patient to terminate the patient's life.*

I believe that 'terminal illness' should have a definition. There is no definition of it in the bill nor any reference to a definition within any act. There is a need for such a definition because many illnesses may be terminal if not properly treated. Similarly, I think that a 12 month period is far too long. A lot can happen within a period of 12 months to change perspectives.

Clause 5 states that:

*A person shall not give any reward or advantage other than a reasonable payment for medical services or, by any means, cause or threaten to cause any disadvantage to a medical practitioner or other person for refusing to assist or for the purpose of compelling or persuading the medical practitioner or other person to assist or refuse to assist in the termination of a patient's life under this act.*

The penalty is $10 000. I believe this clause requires 4 subclauses because it deals with 4 separate offences, each with a separate degree of culpability and effect. For example, in the second last offence outlined, if a person does compel or persuade anyone to assist in terminating a patient's life, this would amount to assisting in murder. The penalty for that, I believe, is not monetary but imprisonment.

Clause 6(b) says:

*the medical practitioner is satisfied on reasonable grounds that the patient is suffering from a terminal illness and is likely to die within 12 months.*

Again, a definition of 'terminal illness' is required to prevent abuse. The phrase, 'likely to die' is just not good enough. It is too loose and is open to wide interpretation.

Under clause 6(c) it says:

*A second medical practitioner has examined the patient and has confirmed the first medical practitioner's opinion as to the existence and seriousness of the illness and that the patient is likely to die within 12 months as a result of that illness.*

I believe that only 2 medical opinions without any further qualification is not enough. Even in our justice system, to determine the guilt or otherwise in a killing with intent, there are at least 4 steps before final judgment is reached.

---

Under clause 6(d) it says that

*the practitioner must be satisfied that the illness is causing the patient the condition of severe pain or suffering or distress.*

How do you determine this in law? The medical practitioner has to be satisfied of any one of these conditions, each of which is inherently subjective and in most cases may be alleviated.

Clause 6(e) says:

*the medical practitioner has informed the patient of the nature of the illness and its likely cause and the medical treatment including palliative care that might be available for the patient.*

I believe that, in the context of euthanasia, it is dangerous to allow the medical practitioner to be the only one doing this. The certificate that the patient signs says that the patient has been fully informed. But, unless he or she is also an expert, he or she is unable to judge whether he or she has been given all the information or not. Furthermore, the second doctor would also be unable to judge unless he or she was actually present at the time the information was given. In any case, palliative care should not be presented as an option but should be standard. Otherwise, what is the point?

Under clause 6(f):

*The practitioner should be satisfied that there is no medical treatment reasonably available and acceptable to the patient that will relieve the patient's severe pain or suffering or distress.*

The phrase is: 'no medical treatment'. What about other treatment, especially for suffering and distress? I believe that the term 'reasonably available' would have to be tightened. Reasonably available based on whose view? At the moment, it would only be the 2 doctors.

Under clause 6(h):

*the medical practitioner is satisfied on reasonable grounds that the patient is competent and that the patient's decision to end his or her life has been made freely, voluntarily and after due consideration.*

Again, what is meant by 'reasonable grounds'? The practitioner has to act as judge and jury. In addition, the patient is deciding to end his or her life on the basis of information given by the very doctor who will assist in the death. I believe this to be absurd and unreasonable. At the very least, a psychological assessment would be a prerequisite.

4

---

Clause 6(j) states:

*the medical practitioner has witnessed the patient's signature on the certificate of request or that of the person who signed on behalf of the patient.*

This means that the medical practitioner is a witness to the patient's signature. This could lead to abuse. If no one queries the procedure, forgery by the doctor would remain undetected. There needs to be an independent witness to the process. The certificate at least should have the status of a statutory declaration.

Clause 6(m) says:

*at the time of assisting the patient to end his or her life, the medical practitioner has no reasonable grounds for doubting that it continues to be the patient's wish to end his or her life.*

The use of the term 'no reasonable grounds for doubting' lacks clarity. The clause is intended to mean that, if the doctor has any grounds for believing that the patient has changed her mind, then the doctor should not assist. That is how it should be stated.

Clause 9 says that:

*A person shall not by deception or improper influence procure the signing or witnessing of a certificate of request. Penalty: $20 000 or imprisonment for 4 years.*

I believe that breach of this clause is either murder or conspiracy to murder and should be dealt with accordingly, with the appropriate penalty. In any case, there should be severe penalties for the medical practitioner who assists in the death if any of the conditions under clause 6 are not satisfied. In particular, this should be the case if the medical practitioner has any ground for doubting that the patient still wants to be killed and proceeds, or is in fact told by the patient that they have changed their mind and proceeds.

That concludes my remarks as contained in the appendix to my submission.

**Mr POOLE:** Right. Would you like to make any further general comment in relation to your submission?

**Mr HILLOCK:** To sum up, I would say that the arguments in favour of the bill are not strong. Some of the arguments that have been used have tended to be semantic. In fact, when I started to write this submission, I found great difficulty in putting my thoughts in order. That is why I used the points for debate that were outlined in the media release as the basis to form my submission. I believe that the counter argument absolutely refutes these.

5

---

**Mr POOLE:** Thank you. Mr Hillock, whether or not the points that you raise are covered in the third reading speech or by amending proposed legislation, is your argument based on the sanctity of human life as compared to the principle of freedom of choice?

**Mr HILLOCK:** It is based on the sanctity of human life but it is also based on principles of law. For example, anyone can justify theft in certain circumstances but no government and no society can make a law that says that theft is justified. That is why we have courts and judges. The same applies with killing.

We all know that we have a use-by date. We all know, to a certain extent, what death means. But we do not really know the ultimate. We all know that we have to go through it. I believe that this bill was prepared and submitted for the community's consideration after some trauma. Other people have gone through the trauma.

My father was a doctor. His wife was a doctor. He had colon cancer. He lived with it for 12 years. He would not put himself under the knife except at the very last to improve the plumbing. He died without taking drugs and he died at peace. He went through a great deal of pain. He did it purposely. He knew what he was doing and he died with a clear mind.

That is a personal thing but it also means that I know that doctors are no different than you and I. They are subject to the same temptations. They are subject to the same weaknesses. They are human. We cannot give them free reign to kill people because that destroys the whole basis of the profession. If one must think of this, it would be better to appoint a public executioner. But do not give it to the medical profession.

**Mr POOLE:** What is your comment on the public declarations that have been made by some doctors in Australia who are already actively helping people to die?

**Mr HILLOCK:** Every person must make their own judgment on what they do in life. That is their problem and thank God it is not mine.

However, sanctity or the law that governs the liberty of our society must be preserved. If they are freely admitting this, then they should be prosecuted and a judgment should be made. They may be guilty; there may be mitigating circumstances. That is up to the judge in sentencing. But you cannot ignore these things and it is no excuse for changing the law. One of the things that annoyed me about this was that the publicity given to it in the early stages suggested that everybody is going to die in fear, pain, suffering and distress. That is not so.

**Mr POOLE:** But the bill is very narrow in its confines, is it not? It only appears to be applicable to a very small minority of people. I am sure that the proponents of the bill would argue that every individual has the right to suffer a peaceful, painless death. If that is not occurring, they should have the option of saying to the doctor, in accordance with the mechanics of the bill: 'I am asking you to help me out of my constant pain and aggravation and to help me terminate my life'.

---

**Mr HILLOCK:** I would refer you to what I said in the original submission. I quoted Cecily Courtney, who was one of the founders of the hospice movement. She said words to the effect that: 'If any one of her patients asks for euthanasia, then we have failed'.

In the appendix, I have outlined weaknesses in the conditions within the act that would enable unscrupulous people, for one reason or another, to do things. It has happened in Holland. I am sure that we are all aware of what has happened in Holland. It is not an exaggeration. I go back to what I said originally. It is not the doctor's position to go against his oath and his profession, and to kill. If I am suffering and my socalled quality of life is not what I would expect, you cannot stop me jumping off the Katherine bridge. But I am not going to ask you to push me.

**Mr POOLE:** Sure. I think that was one of Marshall Perron's arguments in his second-reading speech. Being an able-bodied person who might for whatever reason have a terminal illness, you might want to jump off the Katherine bridge. What about the person who is in hospital, cannot get out of bed and cannot even lift a finger? In effect, you are denying them the right of choosing to end their life. Every able-bodied person in the community has an undeniable right to commit suicide, not that our society endorses it. At the end of the day, I guess you cannot stop people. What about the person in a hospital bed who cannot do anything?

**Mr HILLOCK:** I will come back to another point that I made. In this modern world of ours, there is too much attention placed on rights without the concomitant responsibilities and duties. Doctors are pre-eminently or professionally involved in a duty of care. The unfortunate thing is the poor individual who is in great suffering. But you cannot put that responsibility on doctors. Nor can we, as a responsible society, negate or undermine the duty of care that is absolutely essential to the medical profession.

**Mr POOLE:** Forgive me for playing the devil's advocate but we have had representation from quite a few doctors. I mean, we have received virtual petitions from groups of doctors who are endorsing the bill. Obviously, some doctors feel that they should have the right without fear of legal recourse to actively terminate somebody's life where the patient has requested it.

**Mr HILLOCK:** As I said before, doctors are human. There are many reasons for people's opinions.

I will tell you another story. When I was a boy, a friend of my mother was a nurse with the British Army. She returned from Germany having been involved in the nursing of survivors from Belsen, a concentration camp. I remember listening to what she told my mother, although I was not supposed to hear. Some years afterwards, I was a young soldier in Germany. So I went to Belsen. Things had been cleared up and so on and so forth. But I saw the graves, tens of thousands of nameless people buried there. None of those things could have happened without the active involvement of the medical profession. The medical profession is not made up of saints. As responsible citizens, we can only see that the law

---

protects our community in general. I come back to my point. You cannot allow any individual to kill with intent. Nor can you allow the medical profession to deny their calling.

**Mr STIRLING:** Mr Hillock, many share your concern about the lack of definition of the term 'terminal illness'. I am one of them and I have written to the Chief Minister about my concerns. I believe that he is seeking to address that in the time before the bill comes before parliament again at the next sittings. Have you given any thought as to how that might be defined or would you say that it is beyond the realms of possibility?

**Mr HILLOCK:** It is not for me to define. I am not a professional medical man. If it is to be defined, it has to be defined in legal terms on advice from the medical profession. As a layman, I would say that one can give opinions. One can say: 'You are likely to die'. I am likely to die by the age of 76; I am surprised that I am still living. So how do you define it?

A doctor will have a pretty shrewd idea of whether somebody has a short life in front of them. They may be able to cut it down to a few weeks. But I doubt that you can really define it within 12 months. In any case, even if you could, you are dealing with the psychology of a patient. I do not know enough about this to know the pain and suffering of the individual. I can sit here and put myself through all sorts of pain and suffering. You can go back to the concentration camp example, for God's sake. People in the concentration camps could still laugh. People can die also because they think life is not worthwhile and they waste it. It is in the mind. I believe that, by and large, most people ultimately die peacefully. But I do not know enough about it. It is very rare for people to die in severe pain.

**Mr STIRLING:** Further to that, you suggest that 12 months is far too long ...

**Mr HILLOCK:** Yes.

**Mr STIRLING:** What would you suggest as a required time?

**Mr HILLOCK:** I do not want to argue for the bill in any shape or form because it is bad law. It is just bad for society. It would have to be within a period of weeks. Remember that we are not talking about pulling the plug or giving endless nonsensical treatment that keeps somebody just breathing and no more. We are talking about actively killing somebody. It is a different thing.

**Dr LIM:** Mr Hillock, you talk about a doctor's duty of care. A doctor's duty of care is to care for the patient. That care can sometimes be interpreted by doctors as meaning: 'I will follow you right through to the very end and if you decide that you no longer want to bear the last 12 months of your life, I will follow you there and complete the act for you'. Some doctors see that as a duty of care. Can you comment on that?

**Mr HILLOCK:** Thank you very much.

Doctor, you can tell me this. I have a quote here from the Hippocratic Oath. I do not know exactly what happens when you train as a doctor but, from memory ...

---

**Dr LIM:** You mention it on page 5 of your submission. Sadly, I have to inform you that, although I took the Hippocratic oath when I graduated way back in the early 1970s, modern graduates no longer take it. I think that change occurred at a time when Australia legalised the termination of pregnancy.

**Mr HILLOCK:** That is sad. Nevertheless, it is only a few years. The Hippocratic Oath goes back almost 1500 years. When you spoke about the duty of care, you almost said it as if you were dealing with a friend. A doctor is by and large dealing with a patient. I presume that they have to be careful that they do not reduce the patient to a number, which is a bigger danger than what you are saying undertaking a friendly action. Nevertheless, I would opt out of it a bit by reminding you that the President of the AMA, in answer to that sort of question, said: 'All right. Maybe we do things that the law says we should not. But we must agonise over those things because they are important. Then we must be prepared to take the consequences because killing someone is a very serious business'.

**Dr LIM:** I suppose the doctor-patient relationship is such that, after going to a doctor for many years, sometimes 10 or 20 years, patients develop a very close relationship with their doctors, not necessarily as a friend but in the context of a pastoral medical relationship. Some of those patients would like the doctor to extend that duty of care through to termination of life. It is not that I am supporting it; I am just putting the question to see how you feel about it.

**Mr HILLOCK:** All right. That is fair enough but, if you do something that is as serious as that, you must take responsibility for it. Good God, we have all done something serious in our lives. When you do it and you are aware of the consequences, you take the responsibility for it. You do not opt out of the responsibility. Otherwise, it is not a responsible decision.

**Mr POOLE:** But it is a grey area.

**Mr HILLOCK:** It is a grey area for the individual. It is not a grey area for the community. The law that governs the society must make the law for the general community. You violate that principle at your peril.

**Mr POOLE:** But I put it to you that there are situations whereby doctors make that choice to assist people to end their lives. A situation may arise in which a patient with a severe cancer or similar illness, after receiving all possible treatment, has run out of options. They return home. Sometimes they go back to the hospital but more often than not they end up back at home, basically to die. Sometimes they are in intolerable pain and they die under the care of their GP.

Because of the current practices of the profession and the laws of the land, the GP is in a situation of signing the death certificate if that person has been their patient over a considerable period of time. There would be no way of knowing whether that person died as a result of the illness, as a result of being helped to die or as a result of treatment given by the doctor.

---

I guess it then comes down to the intent of the doctor. I am sure that all doctors intend to relieve the suffering of the patient. However, the side effect of gradually increased doses of morphine or some other drug, may be that the patient dies.

**Mr HILLOCK:** All right. I would say: so what? Of course you do not know. It is up to the individual's conscience. What we are talking about here is changing the law. We are talking about making this a standard, accepted procedure within society. One can talk very grandly about creating the law for the good of society but you can take it right back to the poor individual. There may be a perception that the individual is old, dying, and useless to their children. This is a common thing and people often say: 'I do not want to be any trouble to you'. The option is given to them. You may have an unscrupulous doctor. Forget about the pain, forget about the suffering. It just becomes a matter of: 'Here is a patient who wants to be put down and that is it'. They will do it. Do not say that this cannot happen. It will happen. Do not say that it has not happened already because it has.

Increasingly, the medical profession is less respected than it used to be. By making them public executioners I am sorry but you have to use such terms community trust is further undermined. It is absolutely essential that the community be able to trust the medical profession.

**Mrs BRAHAM:** Mr Hillock, I am surprised at the way you question the honesty and integrity of the medical profession. I thought you said your father was a doctor. Yet, in your summary, which I might add is a very good one, which highlights many of the weaknesses we see as needing to be addressed in the bill, you have also questioned very strongly whether 2 medical practitioners are sufficient to make a decision in this case. You question whether a medical practitioner is able to determine whether a patient is competent or not. You talk about having a psychological assessment. You are really very strongly criticising the role of the medical practitioner in this. You are aware, of course, that doctors can say no if they do not want to be part of the process. The bill allows them to do that. Can I just ask whether the bill is about the role of the doctor or is it about the right of the individual to make a choice at the end of their life?

**Mr HILLOCK:** It is certainly not about the right of the individual to make the choice at the end of their life. It is about the doctor and giving the doctor society's approval to terminate life.

**Mrs BRAHAM:** You do not think there are enough safeguards in the bill to prevent a doctor doing this without the patient's permission.

**Mr HILLOCK:** No, there are certainly not. The penalties involved are inappropriate. Money is money but a $4000 penalty or even a $20 000 penalty is chicken feed when one considers the insurance cover that doctors must take out. Professional indemnity insurance for doctors would ensure that they have the best legal minds available. When it comes down to questions of malpractice, the arguments could go on forever. By and large, the bad doctor is going to get out of it.

I do respect doctors. I respect you. I respect all people. I know that you are human, just as I am human and doctors are human. Crime occurs.

**Mrs BRAHAM:** But do I not have a right as an individual? Perhaps I am at a very terminal stage of an illness and I say: 'Hey, I have had enough. I want out.' Do you not think that I have a right to then say to the doctor, who I know will do it legally and with protection, to hasten my death? Do you not think that I have a right as an individual in this society to do that?

**Mr HILLOCK:** Anybody who goes through life may find themselves in sufficient pain to say: 'For God's sake, somebody. Blow my brains out! I would not say no'. In a strange way, someone who is in very severe pain and distress is the last person in the world to be able to ask somebody to bump them off. That is almost a paradox but it is true.

We are talking about the law. We are talking about society. We are talking about the rules of society and I come back to my point that it is up to the judge to make the judgment. Some people would say that we should never make any judgment but in order for society to run, someone has to judge. We appoint judges and that is it. By the same token, we do not kill for murder now. We do not execute people. That is why, in the appendix, I say that even in a court of law, there are at least 4 onerous processes even when we are not talking about killing with intent. Here, we are talking about an individual with a doctor. It is a personal relationship. No one knows the content of conversations between them. Yet we are saying that it is perfectly all right for this procedure to go ahead. I think it is wrong.

**Mrs BRAHAM:** I think that is all the questions I have.

**Mr POOLE:** I thank you sincerely for appearing in front of us. You obviously spent a lot of time working on your submission and we appreciate it. I think you have raised valuable concerns which will certainly have to be addressed. It reminds me of some of the nights I spent in the army talking to a friend of mine from Aberdeen. We had long, intense discussions.

**Mr LIM:** Thank you very much.

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 12.15 Pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Margaret O'SHANE

**Note:** This is a verbatim transcript. It has not been tape-checked by the editors.

**Issued: Thursday 4 May 1995**

1

---

**Mr POOLE:** I will not run through it all again. I think you heard what we said earlier about the rules of giving information to the committee. It must be truthful and if you want to say something that is confidential, you should indicate that you wish to do so. Otherwise what you say can be actually used publicly. Are you happy with that?

**Ms O'SHANE:** I am happy with that, yes.

**Mr POOLE:** For the Hansard record, could I ask you to state your full name and the capacity in which you appear today.

**Ms O'SHANE:** My name is Margaret O'Shane and I appear as an individual.

**Mr POOLE:** Fine, Margaret. Welcome. Thank you.

**Ms O'SHANE:** I am not aware of the clauses in the bill. I just wish to make a statement in favour of euthanasia.

**Mr POOLE:** All right.

**Ms O'SHANE:** I speak from personal experience. Excuse me, but I get a bit emotional. I will get over it in a minute if you can just allow me to go on talking.

**Mr POOLE:** Don't worry about that. We have had many discussions in which people experience strong feelings as they talk and we acknowledge their emotion. Just relax and feel quite comfortable. It is not particularly formal even though it might appear so.

**Ms O'SHANE:** I will relax in a minute, thank you. I will just relate my personal experience. I lost my mother about 29 years ago. She had an emergency operation to remove a chicken bone from her throat. At the end of the operation, which took all of 5 minutes, the medical staff left her on the operating table in a state of unconsciousness from the anaesthetic. It was such a simple operation. When they came back to her, they found that she had had cardiac arrest. They estimated the time to be about 4.5 to 5 minutes. In other words, she virtually died on the operating table. Because that is not allowed in a theatre, they did an external cardiac massage and brought her back to life. She was virtually brain dead.

She was actually unconscious for about 12 months and 3 days. In that time, we knew that she was not going to enjoy life as we know it. Her family, including myself, went through all that agonising time and we knew that she was going to die at the end of it. It took 12 months and 3 days. We then had to go through the further trauma of the loss of a mother.

I come from a family of 5. My youngest brother was 17 at the time. My sister, who was the eldest, was 24. It was quite a young family that she left behind. I actually did nursing for quite a number of years and I happen to have worked in the hospital where she was a patient. I was not there at the time, however. I know the pros and cons of the medical profession but for the sake of the family, in some cases I think it is better, not just for the

---

person not to suffer although I believe that my mother never suffered because she did not know anything particularly but for the people who are left. As I stated earlier, it was not just once but twice that they suffered.

**Mr POOLE:** Can I ask you about your mother. Was she kept alive by a machine, by a respirator or a ...

**Ms O'SHANE:** For the first few weeks after the operation, she was. But then she reached a level of consciousness or unconsciousness or something, where she could survive the rest of the time without artificial aids. After the first 3 or 4 weeks, the only thing they did was to feed her through a tube. It was just left then for her to die naturally. As far as I know, no medication or anything was given to help her along.

As I stated earlier, I have been a nurse myself and I have seen a number of cases where patients were kept alive by the use of what were considered to be modern drugs at that time. I will refer back to my mother because in that 12 months and 3 days when she was kept alive, she had more money spent on her than my father was able to earn in the whole of her life. We were brought up very poor as far as money standards go. We were very rich in love and family.

**Mr POOLE:** I know what you mean.

**Ms O'SHANE:** I do not see us as a poor family in that way. I felt that we had a very rich life. The fact was that it cost so much to keep a person alive like that. It has to be paid for by somebody and normally it is the taxpayers. I am now being a bit clinical, if you like, in that we have to think about the financial side. I do not mean just the family; I mean the whole of society. I think that it becomes a little bit hypocritical sometimes when it is going to cost society a great deal of money to keep a terminally ill person alive while there are so many other areas in which money could well be spent to keep other people alive.

**Mr POOLE:** Margaret, from what you have said, your mother's case would not be covered by the bill that is proposed. That is because some of the conditions of the bill are very much along the lines that the person must be mentally competent. In other words, they must be able to request their own death and they must have a terminal ...

**Ms O'SHANE:** In that case, people around her the family in particular should be consulted about how they would they like to go.

**Mr POOLE:** Without knowing the full history of what exactly happened and I am sure that Dr Lim would be in a better position than I to comment it is likely that your mother would be covered by the provisions of the Natural Death Act. I am not sure about the situation if a person is not on a machine. If she was staying alive without assistance, she would not be covered.

But if a person needs that assistance to stay alive, nowadays you can ...

3

---

**Ms O'SHANE:** Yes, but I do not think that the argument is about what happened with my mother. I think my argument is about whether euthanasia should be legalised. They did not have any bill at that time, which was about 30 years ago, and they probably would not even have thought about it.

**Mr POOLE:** You are really arguing from the point of view of freedom of choice.

**Ms O'SHANE:** In a case like that of my mother, where a person is not able to speak for herself, the decision could be made by members of the family.

**Dr LIM:** Thank you very much for sharing your own life experience. It must have been very traumatic for you when you were so young and it went for so long. Sometimes, in a case like that of your mother, medical science is not able, and 30 years ago was not able, to predict what the outcome might be. That was the reason your mother was resuscitated and maintained for at least the duration until she was able to maintain her own life without external support. They had to give her that chance in case she did recover.

**Ms O'SHANE:** I have my own views about that and I do not think this is the forum to discuss them. They do not really run along the same lines and I could talk to you about them afterwards.

As I said, I have nursed and seen patients in various situations. I think my argument in this case is also to do with the financial side of it. Society as a whole has to carry these sorts of cases and I think that is something that people do not really think about. I think emotion carries them along when it comes to whether they are for or against voluntary euthanasia.

**Dr LIM:** I am sorry. The converse of the argument was that doctors and nurses could be covering their own backsides as well.

**Ms O'SHANE:** Sorry?

**Dr LIM:** The medical profession could be covering themselves. That is the converse of the argument about what happened to your mother. The doctors could have been doing it to cover themselves. When it comes to euthanasia, however, this bill only relates to patients making the request themselves. It would not allow external bodies, whether they are part of the family or not, to make the decision. It really does not cover cases such as that of your mother. That is the difficulty.

**Mr POOLE:** One of the perceived difficulties with the bill, in the view of a number of witnesses, relates to the argument that you put in favour of the bill, concerning financial aspects. Some people, particularly nurses and doctors who look after the elderly, argue that the bill might change after it has been introduced and that nonvoluntary euthanasia might then take place, with governments using it to keep their medical costs down. They might say: 'We have a nursing home full of aged pensioners, most of whom are going to die within 10 years, so we might as well start speeding things up a bit so that we have more money to spend on younger people in our society, premature babies and so forth'. What do you think about that?

4

---

**Ms O'SHANE:** I am a bit tired. I am sorry; I have been up since 4am. If I can follow your trend a little bit ...

**Mr POOLE:** You were talking about taxpayers' money.

**Ms O'SHANE:** Yes. When you were talking about the elderly, I was thinking. That is probably why I missed a bit of your question. In some cases it is not just the elderly who have terminal illnesses and who need to be able to die with dignity. I guess I missed your point a little bit. Are you referring to termination of pregnancies or something?

**Mr POOLE:** No. I was referring to the argument that is put by some people who are against the bill. They are saying that whilst this bill is about voluntary euthanasia people who are requesting to be put down at some time in the future it could be changed to cover people who do not request it, such as people who are hospitalised, old or infirm. Other people might say: 'It is costing us a lot of money to keep these people alive. If we just give them an injection, we can save a few bob for the taxpayer and we can spend it at the other end of the spectrum on newborn babies or premature babies, where the costs are very high'.

**Ms O'SHANE:** If the bill did pass, there would have to be a watchdog on that so it would not become open slather. Is that the response that you are ...

**Mr POOLE:** I was just interested in your response, yes.

**Mrs BRAHAM:** Margaret, I hear what you say and I think you are simply saying that you are in favour of euthanasia because there are certain cases where it is better not just for the person concerned but for the family, because of the pain and suffering that is involved. You are also arguing that it is a good thing because then the budget can be looked at in other ways as well. Are you also saying that you believe that people should be able to determine whether they want to die by choice if they are terminally ill? Are you talking about people having a right of choice?

**Ms O'SHANE:** I think that people should have a choice, yes.

**Mrs BRAHAM:** We are not just talking about the elderly.

**Ms O'SHANE:** No.

**Mrs BRAHAM:** Sometimes that tends to overwhelm this argument. People seem to think that we are only talking about the elderly having terminal illnesses.

**Ms O'SHANE:** I have seen cases from young teenagers to the elderly who have been in that position. If they had had a choice, their suffering would have ended much earlier than it did.

---

**Mrs BRAHAM:** So it is a terminal stage of an illness no matter what age. We are talking about people say, over the age of 18, having the right of choice to say: 'Hey, I have had enough. Let me out'. I think that basically sums up your argument.

**Ms O'SHANE:** Yes. I have nothing more to say.

**Mr POOLE:** All right. Thank you very much, Margaret.

**Ms O'SHANE:** Thank you.

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 12.30 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Mr Timothy GOUGH

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** On behalf of the committee, I welcome Mr Gough who is appearing as a witness to give evidence. Other than in exceptional circumstances, witnesses appearing before the committee are not required to take an oath or an affirmation. However, I remind you the information you give to the committee must be truthful. For the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you advise us now if that is the case. Are you happy for what you say to be made public?

**Mr GOUGH:** Yes.

**Mr POOLE:** Fine. For the Hansard record, could I ask you to state your full name and the capacity in which you appear today.

**Mr GOUGH:** My name is Timothy John Gough. I appear as a private citizen.

**Mr POOLE:** You can go ahead and address the committee and we can ask questions when you finish.

**Mr GOUGH:** I might be old fashioned but I have always known Australia to be a Christian country, standing on the rules and regulations laid down in the word of God. The laws that we have in the land today all stem from the original Ten Commandments with a lot of added provisions to cater for individual cases and situations and to cater to man's so-called rights as a human being. The original law as laid down says: 'Thou shalt not kill'.

In this case, it is about the individual asking for their own life to be taken and the doctors taking their life. That is classed as killing. No matter how humane it may seem, it is still classed as killing. If you change the law to say that it is okay to kill, where does that leave society? Where does that leave the murderers who go around and blatantly kill people just for the fun of it?

Euthanasia just helps the case along. Where is the judicial standard in that area? Also, if you take a person's life under euthanasia, you are still accountable whether you believe in God or not. Whether you believe God exists or not, we still basically follow his laws and his word. He says that we are going to be judged and be called to account for the things that we do on earth. There is going to come a time when mankind stands before the maker. He will ask: 'Why did you do that?' The answer might be that it was law. But it is not God's law. It is a change just to suit man.

Earlier you mentioned individual human rights. Life is a God-given gift. You did not give yourself life. Your parents did not give you life. That life came from God and God has the right to order your life. We have a right to go along with what God has planned for our life because he has given it to us to start with.

**Mr POOLE:** What do you say to people who are not Christian, who do not believe in God and ...

---

**Mr GOUGH:** People who are not Christian? If I am wrong and you are right, then ...

**Mr POOLE:** No. I am not adopting a personal position. I am just asking what you feel about ...

**Mr GOUGH:** I know what you Are saying. I am answering your question. If I am wrong and you are right, you have nothing to worry about. But if you are wrong and I am right, where does that leave you?

**Mr POOLE:** I would say to you that if I was not a Christian and I should hasten to add that I am then it really would not bother me, would it?

**Mr GOUGH:** It will one day.

**Mr POOLE:** In your opinion. But in my opinion it probably would not if I was not ...

**Mr GOUGH:** Yes, and at the present time it may not. It is not a question of whether you believe in God or not, although people who say that they do not believe in God are just fooling themselves because every man is aware of the knowledge of God. Whether they block it out in their minds or not, they still know in themselves that there is somebody greater than them because the things in the world cannot just happen.

**Mr POOLE:** But there are many nationalities and races that ...

**Mr GOUGH:** Yes, but they all believe in some form of God or being greater than themselves. Even the majority of pagan religions still believe that they will stand before their maker one day. Even heathens and whatever still believe. If mankind turn around and say that they do not believe in God, then they are only fooling themselves.

**Mr POOLE:** In the past, even in our society, life has been taken with the agreement of the people. I refer, of course, to capital punishment. In the Northern Territory, that was only changed in about 1968.

**Mr GOUGH:** Capital punishment also came down as part of God's law. It says: 'If you take, yours shall be taken'. God's law has laid down those capital punishments. Through human rights, mankind says that we cannot do that and instead we will put them in jail for life. Jail used to be a terrible place. It is not getting that way. Prisoners have rights today. At least in my eyes, if you take somebody's life you have given up all of your rights and are liable for the due punishment.

As an individual, if I break the law, then I under all my being stand accountable for what my punishment is. If I take somebody's life, ultimately my life should be taken. That is what God's word says. It might not seem humane. That is the law. It is God's law. It might not be the law of the land today. There are still places in the world that have capital punishment.

---

No matter how terminally ill a person may be, it is still not right to take that person's life. Neither doctors nor anybody else has that right. Suicide is still taking your own life. You are still going to face your maker. If you take your life, you are going to stand before God when he says: 'I said do not do that. You cannot come in'. That is the ultimate punishment. That is the ultimate stand.

God's word also says that if you condone those things, whether you give that person the injection or not, you are accountable. You have as much as guilt as the person who did it or the person who asked for it. Are you prepared as a committee to take that stand and say: 'Okay, we will condone this'? If you do, when you stand before God whether you believe in God now or not, you will one day you will be held accountable for those people's lives. That is what it boils down to.

**Mr POOLE:** I guess we end up answering those questions at the ballot box.

**Mr GOUGH:** Yes. But I know what my vote is.

**Mr POOLE:** We appreciate your view. I think yours is a very common stance, certainly in the evidence that the committee has been given. People seem to either accept the idea or they do not. Religious beliefs are among the many grounds for not accepting it.

**Mr GOUGH:** I have viewed many people dying. I was not there when my father died but I have been with other people as they have died. It is not a pleasant thing. But I have also been with people who have been Christians all their lives or for a fair part of their lives, and have lived for Jesus. Their passing has been a joyous time and a peaceful time. Death is not meant to be a pleasant thing. It is not part of God's plan for people to die. It was not his original plan for people to die. It was through sin that death came. When you look at that, you realise that death is not a pleasant thing and God has no pleasure in it.

**Mrs BRAHAM:** Timothy, I respect your views but do you also respect other people's right to have a different religious view or a different atheistic view?

**Mr GOUGH:** Yes.

**Mrs BRAHAM:** I guess we are talking about a law for society generally, so that people still have that right.

**Mr GOUGH:** Is Australia classed as a Christian country?

**Mrs BRAHAM:** I do not know whether it is any more. It think it is about 40%. It is changing in structure so much so rapidly. It may not be the case any longer. I cannot tell you straight out.

**Mr GOUGH:** But when you stand in court, they will give you a Bible and say: 'Swear to tell the truth on the word of God'.

---

**Mrs BRAHAM:** That is right.

**Mr GOUGH:** If it is not a Christian country, why would they do that? Why even stand to the laws that they have, which stem from the Bible in the first place, if they are not going to class themselves as a Christian country?

**Mrs BRAHAM:** But our constitution would also say to you that you cannot force your religious views on me. No one can force a religion on an individual.

**Mr GOUGH:** Yes, that is right.

**Mrs BRAHAM:** They still have that right of choice. I guess that is what you were referring to when I said earlier that this bill is ultimately about choice, the individual's rights.

**Mr GOUGH:** I had another point about what you said about so many doctors being in favour of euthanasia.

**Mr POOLE:** There are probably just as many who are against it.

**Mr GOUGH:** A fair number of people in Australia make their living from stealing from other people's houses, breaking and entering. It is the same as putting together a bill which says: 'We should legalise break and enter because this is the way we make our living.' It is the same thing.

**Mr POOLE:** I do not really see the analogy. I think in this case you are talking about what you see as the sanctity of human life and what I perhaps see as freedom of choice for the individual.

**Mr GOUGH:** Yes.

**Mr POOLE:** At any rate, I think we will break for lunch at this point. Thank you very much for appearing, Tim.

**Mrs BRAHAM:** Thank you, Tim.

**Mr STIRLING:** Thanks, Tim.

**Mr POOLE:** The committee will resume at 2pm

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 14.00 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Rev. Michael READING

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** I call to order this meeting of the Select Committee on Euthanasia and welcome Mr Michael Reading who is appearing as a witness to give evidence. Other than in exceptional circumstances witnesses appearing before the committee are not required to make an oath or affirmation. However, I remind you that the information you give to the committee must be truthful. I advise that for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right however to request that their evidence be taken in camera and/or remain confidential. Would you please advise us now if that is the case?

**Mr READING:** No You can use it.

**Mr POOLE:** All right. For the Hansard record, could you please state your full name and the capacity in which you appear today?

**Mr READING:** I am Michael Reading and I am a minister of the Assemblies of God Church. I would also like to go on record as representing my own views as a private citizen. As a minister, I do also represent a church.

**Mr POOLE:** Fine. We will adopt the same principle that we have been using, and allow you to say whatever you want to say before we move into a question and answer session.

**Mr READING:** Okay. One of the things that I would like to mention it may be a point that is lacking in me but it is also lacking in a lot of people is that we did not realise that this forum was on until we were telephoned last night. Nor did all the people who were with us, even people from the medical profession. I remember several weeks ago seeing something about a submission to Darwin but I did not realise that there was going to be something here. On an issue of this intensity, I think information needs to be spread far more widely. Like many others, I do not always have time to read the whole paper and, like many others, I never saw a notice about the meeting. A number of people from all walks of life were at my place last night.

None of them knew ...

**Mr POOLE:** Well, I apologise on behalf of the committee. Of course, we can only go so far. We have made a number of press comments and interviews in which we have stated that we were going up and down the track. Advertisements were placed in the Centralian Advocate, the NT News and your local paper.

**Mr READING:** Was it placed in last week's edition? I looked through it and I could not find it.

**Ms HANCOCK:** I am not sure about the actual timing. Was it in yesterday's paper?

**Mr READING:** I went through it and so did my wife. I could not find it.

**Ms HANCOCK:** It was possibly today.

---

**Mr READING:** But with people who are working through the day ...

**Mr POOLE:** Sure. Our difficulty is that we have been instructed by the parliament to report by 16 May. We are trying to be as accessible as possible to as many people as possible. I know the ABC News and Imparja have carried items about the committee's movements up and down the track. I apologise. I am afraid that I can do no more than that. We take your point.

**Mr READING:** That is okay. It is just that I know that there are a lot of other people who would have been interested. People are busy with life and you do not always pick up these things. Something of this importance especially needs to be picked up because it is supposed to represent the views of the people. It is very hard even to do a submission. I have never put in a proper submission and I would not have a clue how to do it. To me, that cuts out a lot of people who feel unable to do it.

That is why I personally feel that it would have been better to have a public meeting at night so that people could have given their views or at least have heard about the issues. I think a lot of people do not understand the issues. One of my concerns is that it seems that the bill is being pushed through as fast as possible to get it over and done with. As an individual, I really feel that it should not be pushed through. Nothing should be pushed through this quickly when it has so many ramifications for the future. Far more time should be taken to consider it.

When we were first developing our petition for this sort of thing to happen, one of the guys who was willing to sign it thought that we were talking about youth coming from Asia and he was not an uneducated person. That gave me an indication that people really do not have a working understanding of what we are talking about here. That is one of the things that I would like to point out. I would like to see a fair bit more time before the bill goes before parliament, so that the people have more time to understand the ramifications.

The bill seems to be about the issue of the individual's right to choose and whether people should have the right to determine whether they live or die. That is what is being debated here. Even though that may not cover all the ramifications of euthanasia, it certainly opens the door in that direction.

I am sure that people here do not want to get into the issue of abortion. However, it shows how someone's right to choose will always invalidate the rights of others. In the case of abortion, those others include: the baby, the father of the baby, the grandparents, and people who cannot have children who may be able to adopt. Our right to choose does affect those around us. We cannot take away from the actual issue that, as we have a right to choose, it does affect those around us. When a person takes their so-called choice to rape or to break in, it does affect those around us.

My example about how abortion on demand affects other people is also relevant to this matter of terminally people ill people having a right to choose. My concern is not just about this particular bill. It is what it could open up in the future. I think that we would have to be naive not to see the danger. By opening the door even 2 inches, there are ramifications which go much further.

---

That is very clear when you see some of the people who appear on TV. I do not know whether you would call them right wing or left wing. A professor popped up on the news quite a while ago and said that, as far as he was concerned, none of the bills go far enough and that people over a certain age should be refused medical treatment and premature babies should never receive treatment. If that is the thinking of a lot of people who are pushing this particular bill, we are in danger of opening up a floodgate which cannot be closed.

In Holland, and earlier in Germany, we have seen what can happen if the door is opened. When they came to trial after the war, 20 Nazi doctors gave the same type of justification for their actions as many of those pushing for euthanasia are giving today. I personally think we must learn from history. If we are not extremely careful about going forward, we can open the door to exactly what happened in other countries. We need to take note that, as human beings, we can go the same way as what other nations. What happened in Germany did not occur overnight. It was actually begun before Hitler even came to power. It was a gradual thing and we need to be aware that such a thing enters into it.

I am appreciative of Tim, the guy who was here before, because I hold his views. However, I think it is far more than a Christian and non-Christian issue. I have also picked up from some of the people who have been talking, that they are trying to make it a Christian and nonChristian view. A lot of nonChristians do not hold support this bill. The issue has to get away from that aspect. It can be very dangerous to take the issue away from euthanasia on to your personal beliefs, whether you are a Christian or whether you are not a Christian.

Not all but many people in and outside the medical profession are in danger of actually invalidating the lives of our soldiers who went to fight wars for the sanctity of life. That is why a lot of them went and died. They wanted to preserve the sanctity of life. I think we need to really think seriously because the ramifications go far further than that. Those men and women gave their lives to protect us.

The other thing was the cost of the patient. What is the cost of going to war to see a country freed? To me, the cost of things should never come into the issue because freedom is something which our whole way of life is actually based on.

When I looked at the clauses, I saw that clauses 3 to 5 and from 5 right through to 14, are all very much open to abuse. One of the things which has been publicised is that a lot of the medical profession has already stated that they are already doing it. If it is now illegal, as far as I am concerned it is classed as murder. If we have not been able to police it so far, what makes the committee or the government think that these clauses are going to make it any different? How are they going to police all these clauses when the doctor can do it?

There was a statement, and I am having trouble thinking of the words, about whether we question the doctors in that they are not sincere. The fact is that some doctors are not. If we have a bias towards one thing, it is very easy to find someone else with the same bias who will do exactly the same thing. The guy who was here first stated a lot of things and I quite agree that it has to go further.

If it goes that way, it still has to go further than just 2 doctors. You see, even though I disagree with it, if it does come in which is beyond my control I would still like to see it being taken care of by more than just 2 doctors. Overseas things have shown that it does lead to people taking other people's lives. One instance was given where a family wanted to go away on holidays. They asked for their father to be put down so that they would not have to be inconvenienced by having to come home for a funeral. There are callous people and not everybody is like that. To me, it is a danger that we need to watch and be careful about.

**Mr POOLE:** With respect to that, Michael, the bill specifically does not cover those sorts of situations.

**Mr READING:** Yes, I know that.

**Mr POOLE:** However, we accept that a lot of people are worried about a possible broadening of the act at some time in the future that perhaps would allow people to do that. I am sorry to break your train of thought but, very quickly, the other point is that it is not a government bill. It is a bill proposed by a member of parliament but he is doing it as a private member. It does not have government status and it will be voted on by all members of the House.

**Mr READING:** That still carries power because of who he is. He carries more power than somebody like me. Those are the actual implications that we have to look at.

**Mr POOLE:** Sure.

**Mr READING:** If we only look at this bill for what it is, I can win any argument by confining the discussion to a very limited area and not allowing people to bring up the causes or the effects afterwards. I could limit the argument and win it even if I was totally wrong. If we limit the argument to this specific bill, I think we are doing an injustice ...

**Mr POOLE:** We are obviously not doing that. I am just pointing out that one of the things that this committee wants is people's opinions so we can take any doubts, grey areas or disagreements to the parliament and put the case to the parliament so the matter is discussed properly. So we are certainly not limiting the conversation. However, I simply point out that, if you say that the bill says something which it does not say ...

**Mr READING:** Well, it does not say it. However, as I pointed out when I first started, we cannot just confine it to the bill. We have to look at where this type of thing has led in the past. That is because there is a very real possibility for this bill to lead this country in the same direction.

I know that I can put something to my church members and I can word it in such a way that it could achieve something later on that they may not agree with. But I can do it. I might do it without meaning to do it. That is why we have an open discussion, so that people can actually look at the ramifications of the whole issue. My personal thing is that I would like to see far more time given to the public, not for education as such but for understanding. That is because a lot of people can have a whole lot of knowledge but not have the understanding and not be able to see the ramifications of what this could be.

That will take time. Overall, I would like to see far more time taken. I know that I have not really looked at the issue of euthanasia until it has started to come up during the last few months. I have had to start to try to get an understanding so that I really know where I stand myself. Even today, I know where I stand in relation to the sanctity of life, but there are far more issues to be considered than just my point of view on the sanctity of life. I am not an educated person, so it takes me a long time to get the brain working to understand it. Given time, I can understand it. I feel that there are a lot of other people who are in the same boat as I am and probably a lot worse than I am.

**Mr POOLE:** We appreciate your thoughts. Are there any questions?

**Mr STIRLING:** Michael, to follow up Eric's comments about the government and parliament, it is not this committee's job either to support or refute the bill. It is very much our job to get information, views and thoughts from the public. That is the process that we are involved in.

**Mr READING:** Yes. I think you were on the committee that came here before to talk about poker machines.

**Mr STIRLING:** Yes.

**Mr READING:** There was a statement made from information that one of you had gathered that the advertising about 2% alcohol was effective. You had the information that there was no more drink. But the next day's paper showed a totally different story. If we had had the paper then, we might have had a different talk. The fact is that, when we look at statistics, we have to be very careful that they are not just the statistics that happen to be available at the time. Given more time, we can have a proper evaluation of what is happening instead of just doing things on the spur of the moment. If something has to be debated in a short time, you tend to just grab the information at hand without really doing a study of the whole thing.

There was something in the paper about the situation in Holland. The argument was that the person who wrote the article on Holland was a crazy person who did not have any understanding, because Holland was a civilised country and would not do something like that. That was the whole gist of this person's argument. To me, that is a very dangerous way to deal with any bill, whether I agree with it or not. You know what I mean. More education needs to be given so that people understand the issues that are at hand and also the future ramifications.

**Mr POOLE:** All right. Thank you very much. It has been very interesting, Michael.

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 14.25 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Mr Keith MAYNARD

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** The committee now calls on Mr Keith Maynard. Good afternoon, Keith.

**Mr MAYNARD:** Good afternoon, Mr Chairman, and members of the committee.

**Mr POOLE:** If you have heard the introduction given to previous witnesses, including the oaths and affirmations, we will not repeat it now.

**Mr MAYNARD:** Yes. I have heard it.

**Mr POOLE:** You do have the right, of course, to request that any evidence which you give be taken in camera or be confidential.

**Mr MAYNARD:** I do not wish to do that.

**Mr POOLE:** Fine. For the Hansard record, could I please ask you to state your full name and the capacity in which you appear today?

**Mr MAYNARD:** My name is Keith Maynard and I am here as an ordinary person and resident of Katherine.

**Mr POOLE:** Thank you. We will adopt the same format, where you say what you want to say and, if we have questions, we can go into a question and answer session later on.

**Mr MAYNARD:** Euthanasia comes from a Greek word and it means a painless, happy death or a peaceful manner of dying. I am in favour of that but I am opposed to the bill.

I believe that legislators take great risks in making laws. Sometimes it is better that the interpretation of law be done by the judiciary rather than by legislation. Examples include the Mabo case, which has been greatly enhanced by the decision of the High Court, and legislation against addictive drugs such as cocaine and heroine, which has caused a great deal of complication. Back in the 1920s, when the Americans tried to legislate against alcohol, it just created a tremendous shemozzle which took years to overcome.

I feel that this bill might also cause some difficulty. In this case of the termination of human life, I think it would have been better had the bill never been presented and the status quo continued. For example, the removal of artificial life support can apparently already occur. I have a daughter who lives in Western Australia. She told me of her friend Jenny, who was in a horrific car accident on 1 March this year. On 3 March, they disconnected the life support. I have not heard of any legal proceedings that are likely to be taken against the people who ...

**Mr POOLE:** It would be covered by the Natural Death Act.

---

**Mr MAYNARD:** Okay. That is fine. I also often hear of cases although I cannot personally quote any in which people who are suffering severe pain are given analgesics and painkillers beyond the safe dose, even though it may lead to their death and often does lead to their death.

Perhaps I should mention something from my own experience. Back in April 1961, my wife was given an injection of penicillin which had a very damaging effect on her brain. I believe the condition is called encephalomyelasia. The effects were almost instantaneous but she lived for a while and she was shifted from Darwin. In those days, the Darwin community was smaller and a very caring community. She was shifted at government expense to the Royal Melbourne Hospital. I went with her in the aeroplane.

She was ill for some weeks. Eventually, the doctors did an encephalogram or whatever. I have forgotten and it does not matter. Eventually, the doctors told me that they would transfer her to Royal Park, which was a mental hospital. They told me that her brain was permanently damaged, that she could be re-educated to use the part of the brain which was still functioning, but that she would not be the same person. I had 4 young children in Darwin at that time and I had to return. On 4 July, my wife's sister rang me to say that she had died during the night.

Whilst I am sure that I would not have been tempted myself, I feel that if there had there been legislation which allowed for my wife to have been killed at that time, there would have been great temptation to do that. It would not have been a temptation to me, however.

**Mr POOLE:** From what you have said, your wife would not qualify under the terms of the bill ...

**Mr MAYNARD:** She could not have given her consent.

**Mr POOLE:** That is right.

**Mr MAYNARD:** It was a very serious thing and people who may have been living in Darwin in those days would remember that she was often screaming. People would cross themselves when they went past when I was visiting her. It was a very traumatic thing but I had 4 children to bring up and I think I did that fairly well.

It is better, I think, to kill the pain than to kill the patient. I believe that. However, we may be stuck with this bill and, even if it is rejected, I do not think the status quo will ever be quite the same. It may not be quite so easy for somebody to turn off a life support system or to give gradually increased injections of morphine which will shorten the person's life. I believe that, rather than being a help to patients, this bill may be a help to people who may be involved in the death of any person in that situation. It may help them to get off the hook if they are taken to court. I object to the bill for that reason.

However, I think it may become law eventually. All the other states have been stirred up by this tiny little place, the Northern Territory. I was therefore very impressed with Mr Hillock's caution about the precise definition of words which are used in the bill. For instance, 'terminal illness'. What does 'terminal illness' mean? We may all be considered to have a terminal illness because we are just a form of animal. We are not meant to last more than about 75 years. I am 74 at the moment.

Mr Hillock pointed out that the word 'reasonable' is used in the bill quite often. What does the word 'reasonable' mean? The men and women who worked under Hitler during his time considered themselves to be reasonable people. Some people who speak today on television programs or write articles are quite surprised that they considered themselves to be reasonable in those days when so many people were exterminated. They are amazed that they thought themselves to have been reasonable then. I do not know what you think about that.

I believe that this bill has opened a can of worms and might lead to quite a few complications in the future if it becomes legislation, as it surely will in one of the states. I think that it is inevitable. Even if it is rejected, we aged people will never be sure that we are receiving appropriate palliative care. Of course, palliative care means to relieve pain but not necessarily to kill the patient. That is what I have tried to express more clearly than I may have before.

**Mr POOLE:** Thank you, Mr Maynard. You raised a couple of points I would like to comment on. In respect of the definitions of words and phrases which are contained in various clauses in the bill, the committee will be examining those with legal advisers. My understanding is that there are legal definitions of what is reasonable. Obviously, the committee will either accept those legal definitions or will question them. If the committee questions them, it will raise them in the parliament in the sense of bringing them to the attention of the parliament and maybe suggesting changes .

**Mr MAYNARD:** I did think of another phrase, which is: 'sure information'. But even that is subject to what people believe the words to mean.

**Mr POOLE:** Yes. However, in the context of legislation, it is not just a matter of going to a dictionary and looking up the word. Most words that are used in legislation have a legal standing and there is a legal definition ...

**Mr MAYNARD:** Yes, I know.

**Mr POOLE:** Such meanings might be different from common usage.

**Mr MAYNARD:** It is good that the legal people argue about the meaning of words because it is the only way that you can ever get a sure definition.

**Mr POOLE:** There is another point which I would like to take up with you. You suggested that maybe judges should be making the laws rather than the parliaments. Of course, that is the ...

---

**Mr MAYNARD:** I said 'interpreting'.

**Mr POOLE:** I thought that you were implying that it was safer for judges to make that interpretation rather than the legislators themselves. I would say to you that the very basis of the Westminster system that we operate under in Australia is exactly the opposite. When we pass bills in the parliament, we have second and third reading speeches and committee notes etc, which are intended to convey to people who want to interpret the law, exactly what the parliament meant at the time the law was passed. Sometimes, of course, the judges in their wisdom agree to differ on our interpretations.

**Mr MAYNARD:** Thank you very much. I was a Clerk of the Legislative Council in Darwin some years ago and I learnt a little bit about that.

**Mr POOLE:** I have noticed your name on many occasions.

**Mr STIRLING:** Keith, I was interested in your comment that, even if the legislation was not passed, there could be a change in the status quo.

**Mr MAYNARD:** Yes, I do not think that things will ever be the same. That is because the issue has been drawn to the attention of the people to such an extent. I suppose this is why politicians or law makers are elected by the people. Ultimately, all governments are answerable to the people, not just at the ballot box but in terms of public opinion. Things are changing all the time and it will not be the same. Perhaps there should be improvement; I do not know. But I am a bit worried that, in the process of improvement, there might be some deterioration in the way aged care in particular is given. I'm involved in aged care. I am a volunteer at Rocky Ridge. I live out; I do not live in. I do not know whether you understand that.

**Mr POOLE:** Yes, I do.

**Dr LIM:** I might follow up on that question. When you say that the status quo will be changed and that you are concerned about the care of aged people, do you believe that this bill, or even the debate on this bill, will change the patient-doctor relationship?

**Mr MAYNARD:** I hope that it does not. I hope that doctors will not feel restricted in telling a nursing sister to increase the dose of morphine or to disconnect life support. Because it has been drawn to public attention, it may have that effect. Eventually, this should be beneficial, I suppose. But I am not sure. There is many a slip between the cup and the lip, isn't there?

**Dr LIM:** Yes.

**Mrs BRAHAM:** I would just like to highlight one of the things you said in your closing remarks, Keith, which has been mentioned by other groups. You said that elderly people may worry now about the care they are going to receive. This bill may plant something

---

in their minds that will cause them to worry about their future care. It has also been said by some of the Aboriginal groups, who do not understand, that perhaps they will lose that confidence and faith in the medical profession because there will always be that doubt that they are not going to receive the care they should.

**Mr MAYNARD:** I wonder about that too. Unfortunately, although we have a number of residents at Rocky Ridge who are Aboriginal people, I am not able to communicate with them. Some people here might know something of the tradition of Aborigines, but I have been told that they probably had their own forms of euthanasia, such as when twins were born. I remember Sister O'Keefe saying that she had to rescue the second member of a pair of twins. This not only concerns infants but also elderly people in a time of drought or difficulty. They went out to the bush and died and this was accepted. Maybe that is natural death rather than euthanasia. It is not hitting them over the head with an axe or something, is it?

**Mrs BRAHAM:** No, no.

**Mr MAYNARD:** I do not know. I do think that we should give an example to the whole of Australia of how to deal with the Aboriginal people. I am not knowledgable enough to give an opinion. I think of Maurice. I do not know; he is looking at me. I have friends, like Peter Jackson. He has an Aboriginal name. It is awful to call these people by a name that is not applicable. He has had a stroke. He tries to talk to me and he gets so impatient. I wish I could communicate.

**Mr POOLE:** Well, you are doing pretty well.

**Mrs BRAHAM:** With us, you are.

**Mr POOLE:** Are there any further questions?

**Mr STIRLING:** Thanks, Keith.

**Mr POOLE:** Thank you very much, Keith ...

**Mr MAYNARD:** Thank you very much and thank you for the way you are listening to all of us.

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 14.40 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Gail HAVNEN (PO Box 943, KATHERINE)

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** Did you hear my comments to earlier witnesses in relation to the giving of evidence?

**Ms HAVNEN:** Yes.

**Mr POOLE:** And do you wish anything to be kept confidential or in camera?

**Ms HAVNEN:** No.

**Mr POOLE:** For the Hansard record, could you please state your full name and the capacity in which you are appearing today?

**Ms HAVNEN:** My name is Gail Havnen. I am appearing as a resident of Katherine.

**Mr POOLE:** Thank you, Gail. Over to you.

**Ms HAVNEN:** My comments will be short, sweet and to the point. Just having listened this morning, I have concerns about the many negative remarks that are being thrown at medical practitioners. It seems that once they were nice family practitioners and that now, suddenly, they are werewolves.

I nursed for 18 years and now I work in community service. In my nursing experience, just to pick up on some of the comments which have been made about older people, I have noticed that they come to terms with dying. They may voice that, saying: 'I sometimes wish that things could end quickly'. However, with all of the discussion that has been generated, some of them may wonder every time the doctor rocks up whether there is an ulterior motive.

**Mr POOLE:** When he picks up a hypodermic, you mean?

**Ms HAVNEN:** Yes. I am not saying that there is hysteria but I think once there was a natural process of thinking of death, as one gets older. Now, there are a lot of extra connotations.

Somebody this morning was talking about unscrupulous people, once again referring to medical practitioners. I would just like to point out that there are unscrupulous people everywhere, from life insurance people to tradespeople.

**Mr POOLE:** Local politicians.

**Ms HAVNEN:** I was not going to mention that.

I think that too much emphasis is being placed on whether a doctor is going to purposely end someone's life without their consent instead of looking at the bill as it is. I suppose it is like reds under the bed. Everybody is looking for all the negative stuff and not coming back to the humanistic side, which is what it is about.

---

In terms of various religious perspectives, many denounce the bill. That is fine for their individual followers but, past and present, many good things and bad things have come from the word 'religion' no matter which god. I do not think that much emphasis should be placed on that because, as we said this morning, Australia is multicultural. A lot of the discussion is getting lost in all these other issues.

I have only just been able to read this so I think there should be a bit more time for community education about processes and procedures. There is nothing here about under-age unconscious people and people suffering a dual disability, such as mental illness plus a terminal illness. I do not know how the bill deals with that.

**Mr POOLE:** They would not be considered to be competent, so the law would not apply to them.

**Ms HAVNEN:** Right, okay.

**Mr POOLE:** Also, the law only applies to those over the age of 18.

**Ms HAVNEN:** Okay. I also think that in this day and age the financial burden should be taken into consideration. That is only because of the patient. Patients often worry and experience stress about how their family will be left. It is a valid concern for the patient and I think it should be recognised that it is an extra burden on them.

**Mr POOLE:** Can I just ask how you would go about that? Under the terms of the bill, either the person asks for the act to be carried out or does not ask. So do you really need to ...?

**Ms HAVNEN**: No, I am just mentioning it because somebody brought up the financial side of it before.

**Mr POOLE:** I see. Yes.

**Ms HAVNEN:** I say that is a valid concern because, if you are terminally ill, you are worried sick for your family that is being left behind.

The bottom line is dying with dignity and freedom of choice. Leave out the suffering. It is the quality of life versus the quantity. That is all I have to say.

**Mr POOLE:** Are you basically speaking in support of the bill?

**Ms HAVNEN:** Yes.

**Mr POOLE:** With the proviso that you think the legislation needs to be tightened up in some areas. In relation to your nursing background, why do you think the bill is necessary?

---

**Ms HAVNEN:** Over the years, I have seen the suffering of the patient plus the family members. People come to a stage where they accept dying and want to die. Even the families, who worry for that patient, may come to that decision. I think there should be something that they can utilise. There is nothing worse than sitting back and watching somebody suffering.

**Mr POOLE:** You are not looking at it from the perspective that watching somebody suffering is causing so much anguish to yourself that it would be easier if the patient was dead?

**Ms HAVNEN:** No, no. I think that dying can be dignified and should be dignified. If somebody has their mental capacities and does not want to continue suffering, and on top of that is seeing their family suffering as well, I think they have every right to make that choice.

**Mrs BRAHAM:** Do you think the family should make the choice or the patient?

**Ms HAVNEN:** The patient should make the choice.

**Mr POOLE:** All right. Thank you very much.

**Ms HAVNEN:** Fine.

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 14.50 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Rev. Jim Winslade, Uniting Church

Rev. Graham Hodgkinson, Anglican Church

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** I welcome Reverend Graham Hodgkinson and Reverend Jim Winslade, who are appearing as witnesses to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise you that for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses however do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case?

**Rev WINSLADE:** There is no need for that.

**Mr POOLE:** You are quite happy for it to be public.

**Rev HODGKINSON:** Yes.

**Mr POOLE:** Gentlemen, for the Hansard record, could I ask you to please state your full names and the capacity in which you appear today?

**Rev HODGKINSON:** I am John Graham Hodgkinson. I appear as the rector of the Anglican Church here in Katherine.

**Rev WINSLADE:** My name is James Richard Winslade. I am the pastor of the Uniting Church.

**Mr POOLE:** Are you both going to speak this afternoon?

**Rev WINSLADE:** Yes.

**Mr POOLE:** All right. It is up to you how you do that. We will wait until you have both finished speaking and then we can ask you some questions, if you are happy with that. So it is over to you.

**Rev HODGKINSON:** I would just like to say that I can understand why some people desire to introduce legislation that allows euthanasia.

My own father died this year from cancer. It was a fairly sudden death but he did have to go through pain at the end. The whole family felt with him and struggled along with him. However, we were grateful that his pain was relieved very well by the palliative care of the people who were present with him. The staff were very concerned that he should not have to suffer pain that could have been a very damning sort of pain without the palliative care that he received.

---

The pain we experienced as he went his pain, prior to his death, sort of helped the family and people who knew him to also prepare for death. It made us aware again that all people die and all need to go through the process of dying. Even though he was going through pain or at least experiencing the care that prevented the pain, it still reminded us that through all that, there is a sort of learning process, even at the very end of life. I guess I have found that, out of all the experiences and different stages of life, there is something to be learned at each. Even the process of dying is a learning process. It just seemed to me that I was grateful to be present at my father's death, right through to the very end. I thought that it would be sad to take that whole process of dying away from people.

I know that euthanasia still involves going through a process of dying and death. However, it sort of adds the dimension of choice as to when that will take place. Normally, death is something that comes gradually and in its own time to each of us. I just thought it would be sad to take away that process of dying.

I agree that life support systems should not necessarily be kept on when a patient is in a coma and doctors agree that there is little chance of that patient regaining consciousness. However, that is a far cry from actually terminating a person's life on the grounds that life is too difficult. I think there would be a sense of guilt if others and the dying person had to make that decision. In the bill that is before parliament, I think it is only the individual person who can really make the decision. I am just concerned that, once that becomes law, the next thing could easily become a process that follows on from there.

I would just like to finish with 3 points. Any law which moves towards euthanasia is, in my view, perhaps open to abuse. First of all, abuse may occur because approval of voluntary euthanasia could lead to the patient feeling perhaps obliged to some extent to ask for euthanasia rather than to remain 'a burden' on their relatives and society. There is a sense in which making the choice a possibility can increase the chances of people thinking: 'Oh, my family does not really want me around' or 'Society does not want me here any more, so perhaps I should take this decision to finish it'. Perhaps that leads to a downgrading of old age. In that context, I would repeat that at every stage of life, we are learning new things, even to the point of death.

The second point that could lead to abuse is that it becomes easier to move towards what you might call involuntary euthanasia. I gather that, in the Netherlands there have been laws allowing euthanasia. The Remmelink Report indicated that as much as 11.3% of the total deaths in the Netherlands in 1990 were attributable directly to involuntary euthanasia. So once there was a foothold, all sorts of reasons appeared to justify people actually being put to death. I think it would be a very sad thing for our community if this bill was even the first step towards such a situation.

The third thing I would say is that it could lead to mistrust between patient and doctor. I think it was just mentioned prior to me appearing before the committee that, if there is a sense in which I perhaps do not have full control over what takes place when I am in my coma, it may lead to somebody making the decision to sort of finish my life for me. I would rest my case there, thank you.

---

**Mr POOLE:** Thank you.

**Rev WINSLADE:** Graham has covered most of what I wanted to say although we did not collaborate in any way.

I have been a pastor visiting hospitals and being with people at the end of their lives for some 30 years. I know the trauma of being the last person sitting with a patient when everybody else feels that they can no longer handle what is happening to their loved ones and relatives. I have lost 2 of my own family with cancer a father and a sister and I have lost my mother through old age and a brother through suicide. I have been through all the traumas and grief.

The main thing I am concerned about is that I believe that the process that Helen Kubler-Ross describes in *Death and Dying* is something that people in terminal illness do go through. They may not necessarily go through the process exactly as she describes it, but people do feel differently at different stages of their terminal illness. It would seem to me to be a very sad thing, if they were going through the process that the death and dying go through, that at a particular stage when they felt depressed because they had not yet come to accept their illness or disease, they actually asked for their lives to be terminated. This is particularly so when, if they move through that stage to a further stage of acceptance, they may decide that they do not want to do that at all.

I think is a tremendous burden on the physician and people who are associated with that person, to know just what stage the person who is in terminal grief is going through. Because if what Dr Kubler-Ross describes is true, and people who have the opportunity to go through that process of getting ready to die are terminated at the wrong point, we actually disrupt the process that most people go through.

That is my main point. I think that we really need to consider that. I have been sitting with people and I have seen them actually go through the process. First of all, they are bewildered. They get angry. They cannot believe that it is happening to them. Finally, they come to a point of acceptance. The point of acceptance is a good point for the family. I just hope that we do not put any legislation in place which will stop that process being worked through. Thank you.

**Mr LIM:** I wonder if you could answer this. Some of the debate talks about the rejection of religious arguments as a basis for our decisions. Looking at Australia becoming more a non-secular nation and society, how do you feel about that being a common argument that religion should not come into this argument whatsoever?

**Rev HODGKINSON:** I do not think that either of the things that Jim and I have raised are really religious points. They are just common events that occur with the dying. I would see my religious view of life, death and rising again as very significant in my opinion about these things but I would not want to impose that upon a multicultural society. I would teach those to my people and to those who come to me but not necessarily on an occasion like this.

---

**Mr POOLE:** Taking up that point, you would impose your view that they should not have the right to make their own choice about dying?

**Rev HODGKINSON:** Not because of my religious views.

**Mr POOLE:** No. I deliberately avoided saying religious views.

**Rev HODGKINSON:** I would oppose it on the grounds that I stated here.

**Mr POOLE:** It is basically the sanctity of human life, isn't it.

**Rev HODGKINSON:** And the process of dying.

**Mr POOLE:** I assure you that I am not being rude, but although people dress up the arguments in terms of what they believe, it seems to come down to a debate about the sanctity of human life on one hand or freedom of choice on the other.

**Rev HODGKINSON:** No. I do not think that it is the sanctity of human life. I think it is he process of dying for all people, which does include freedom of choice.

**Mr POOLE:** Good. Okay.

**Rev WINSLADE:** If I could just respond, I believe that everybody has a belief system of some sort. I believe that even atheists have a belief system of some sort. They may not necessarily believe in the supernatural but it is a belief system. I do not think you can divorce this debate from belief systems. Whatever the belief system is whether it is Buddhist or whatever it will play a part. I do not really think there is such a thing as a totally secular person without any belief system. I think we are trying to be fair to all belief systems.

**Mrs BRAHAM:** I noticed that you were concerned about the move to involuntary euthanasia. We basically had some evidence from doctors who say that it is happening anyway at the moment; so it is being done illegally. One argument for the bill is that legalising it will at least put it on the table. If it is happening involuntarily, making it legal will allow us to know how much it is going on. We will be able to control it to make sure that it is not involuntary, so that it is voluntary euthanasia for people who really want it. Would you have any comment on that?

**Rev HODGKINSON:** Yes, I would have a strong comment. I tend to feel that it really does not follow. Once you begin to make it legal, it bursts the bonds. There is nothing to retain it or keep it in. This has happened with abortion and all sorts of things. Once there was a way through, even though people tried to tie up all the ends, there seemed to be no end to the flood that suddenly came. I would tend to feel that the Netherlands situation would also occur here.

**Mrs BRAHAM:** So do you think we should basically turn a blind eye to what is happening?

---

**Rev HODGKINSON:** No. I would say that the law should remain and that the law should be maintained.

**Rev WINSLADE:** I think that there are situations in which there is tremendous responsibility on the casualty area. A patient may come in and the physician or whoever is in charge has to determine whether to ventilate the patient or not. That, in itself, can be a decision between life and death. So there are grey areas already. However, I agree with Graham about what could happen if we legalise it.

I can remember in my lifetime the situation with divorce. We always said: 'Divorce is okay as long as you are not the guilty party'. Then we had people trying to come up with evidence to prove that the other party was guilty. They did that in order to get out of the marriage. Now we do not even worry about that. We have moved a stage further. For ease of access to divorce, we have moved along the line. I can see that with law, you can easily do that. You may start with a stated principle but then you may move to a lesser principle just for ease of access or ease of delivery.

**Mr POOLE:** You are quite right, of course. The argument has always been that voluntary euthanasia will move down the path to involuntary. I guess the answer to that it is a possibility because legislators can simply change the law.

**Rev WINSLADE:** Yes. That is right.

**Mr POOLE:** One would like to think that, in our society, if legislators tried to change the law from A to B in that particular case, somebody would kick them out of office.

**Rev WINSLADE:** I would like to see a referendum or something. I think that would be the fairest way to gauge what people believe. If we have a small group of parliamentarians making the decision, even on the basis of the evidence you gather in a committee like this, you are only dealing with a small sample of what people think. I have heard people say that they did not know these meetings were happening. There is a wider and larger group of people who are interested. An issue such as this, which affects the very fabric of our life, needs something like a referendum to determine. It is too risky for people in public life to make the decisions. I think that we need a wider ...

**Mr POOLE:** Just out of interest, the indications from a polling perspective, and I appreciate very much that that is not a referendum ...

**Rev WINSLADE:** Yes.

**Mr POOLE:** ... that the country would probably be in favour of it. Then again, we can argue the same thing for capital punishment. The country is definitely in favour of capital punishment but no government has passed a bill to put it in place. That comes back to the moral and ethical focus, I guess.

---

**Dr LIM:** Perhaps just a bit of information for you, Jim. Kubler-Ross's 4 phases are denial, anger, depression and acceptance.

**Rev WINSLADE:** Thank you. I have become a bit hazy about them. I knew that I had studied and read them.

**Mr POOLE:** We are well versed, even the doctors amongst us. Thank you.

**Rev WINSLADE:** Yes, thank you..

**Mr POOLE:** All right. Are there any further questions? Thank you very much, gentlemen, for your time this afternoon.

**Rev HODGKINSON:** Good, thank you.

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 15.05 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Mr John R Donnellan

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** If you let me run the meeting, I will tell you what we want to know. We would like to start with your name.

**Mr DONNELLAN:** I am Tig Donnellan. My occupation is cranky bastard.

**Mr POOLE:** All right. Well, don't get too cranky. We have a procedure in front of this parliamentary committee. Basically the procedure is such that you can make your submission and we can ask you questions. We do not ask you to take an oath or an affirmation but we do require the information you give to the committee to be truthful. You should realise that you have the right to say something that can be taken confidentially or in camera. Otherwise, whatever you say might be used in public. If you want something to be taken confidentially, you should request that now. Are you happy to proceed publicly?

**Mr DONNELLAN:** Yes. I am quite happy, thank you.

**Mr POOLE:** All right. For the Hansard record, state your full name please and the capacity in which you appear.

**Mr DONNELLAN:** John Ramsey Donnellan. The capacity is a cranky bastard.

**Mr POOLE:** Okay, over to you.

**Mr DONNELLAN:** Well, to my way of thinking, you are going about this the wrong way. You are going around asking people's opinions of what they think about euthanasia.

There is a lot of evidence that the pros and cons have not been put in front of the people. You are picking up people's opinions. They might have a religious conviction that this is the way they think, or observation or whatever. There is for and against in this. What I would be doing, I would be jamming that mob of cowboys in the ABC to put on a program including people who can speak quite well, like that Yankee doctor that was here last weekend. He spoke quite well. He got his point across very well.

You put it up and you get: 'Why I am in favour of euthanasia and this is my opinion'. These are the people who speak, all right? Then you get the other mob that do not believe in it saying: 'Well, this is why I do not believe in it'. Then they give their reasons. That way, you are putting it in front of people. Then they have a little bit more information about the whole problem before you ask their opinions.

You know, I have picked up stuff from television and observation and my own personal convictions about the problem. The problem is that, when you start killing people, you are in a lot of trouble. You get the Dutch thing. This is what I picked up from the newspapers about the Dutch experiment with euthanasia. There have been 1000 people killed who were not supposed to be. Then, in some other hospital, someone was due to have his left foot cut off and his right foot got cut off. You know, there are all sorts of stuff-ups.

---

Then you have the problem of people with degenerative diseases. I saw on television where a woman who had some degenerative disease. I do not know what it was but apparently it progressed to the stage where she became immobile. She had no control of her limbs and she could not talk. I think the only thing she could move was her eyeballs. I am not too sure whether it got to the stage where she could not even move them. This is going back a few years. She wanted to be put down because she felt that she had absolutely no feelings or could not think or whatever, to the stage where she was just a vegetable.

**Mr POOLE:** Under the terms of the legislation, that we are discussing, she probably would not qualify because you have to basically be mentally competent.

**Mr DONNELLAN:** Yes. Well she made the decision when she was mentally competent knowing that later on she would not be competent.

**Mr POOLE:** That is not the purpose of this legislation. This legislation quite clearly says they must be mentally competent when it happens.

**Mr DONNELLAN:** Well, I do not know about that one. But there are things for it and there are things against it. People need to have the whole range of arguments put in front of them. A television debate or discussion would be a good format.

**Mr POOLE:** Yes. There has been a fair amount of discussion in the community for a fair amount of time. However, it is one of those things that has been brought to the fore simply because the bill came up in the Northern Territory. The Right to Life group and the Voluntary Euthanasia group have been pretty active but not so much in the Northern Territory. We accept that and I note your comments. We are a committee that has been told by parliament to get out and do this job and we are doing it in the best way we can in the time available.

**Mr DONNELLAN:** Yes. You see, I do not really think that people can formulate an informed opinion unless they have the whole range of information. You get the proeuthanasia people putting their argument and, the way the world is going, the twisting of the facts to suit the case in both sides comes out. You can see this in public life all over the world.

**Mr POOLE:** Our job really is to highlight those points and bring them to the attention of the parliament.

**Mr DONNELLAN:** Well, I do not know whether parliament is the best place. You see, you start legislating things ...

**Mr POOLE:** It is parliament that is going to pass the law or not.

**Mr DONNELLAN:** Yes, that is the law. You pass the law. Who passes the regulations?

**Mr POOLE:** Parliament passes the regulations.

---

**Mr DONNELLAN:** The public service regulations?

**Mr POOLE:** I do not think you would have public service regulations with respect to this particular bill.

**Mr DONNELLAN:** Well, someone is going to have to police it.

**Mr POOLE:** The parliament polices it.

**Mr DONNELLAN:** You mean you are going to hop off down to the hospital to have a look at the death certificate or whatever?

**Mr POOLE:** Oh no, no.

**Mr DONNELLAN:** That is done by bureaucrats, mate.

**Mr POOLE:** Yes. I realise that but you are not going to be in a situation whereby bureaucrats are going to draft regulations about dying.

**Mr DONNELLAN:** No, but they draft the procedures that are followed. When you get a death certificate and the regulations say that something in it ought to be checked, someone has to go and check it.

**Mr POOLE:** The system basically is that regulations might very well be drafted according to the terms of the bill by bureaucrats. But they are approved by government.

**Mr DONNELLAN:** Well, I know of bureaucrats who are doing things that are contrary to the bill because they think it is wrong. You could agree with their opinion, that you think they are right. Then you can probably get other people to agree with the way the bill is written and the bureaucrats are doing it wrong. Then you get jumping up and down and the ABC will come along and float around: 'Here is a little bit of stirring. We love this'. They will dramatise it and so on. But once government starts touching things, things go horribly wrong, real wrong. I reckon that is enough. Do you want to ask me any questions?

**Mr STIRLING:** I want to support your point about regulations. Parliament itself does not scrutinise regulations but if there were regulations to be introduced with this legislation, that would only occur after it was enacted.

**Mr DONNELLAN:** Yes, you have ...

**Mr STIRLING:** Let me assure you that I for one would want to know what those regulations were and would be making sure to the best of my ability that everybody else did as well. Your point is valid. Many regulations go through and are simply gazetted that no one knows anything about. I would see this as a very different case. But it is a valid point nonetheless.

---

**Mr POOLE:** Thank you very much.

**Dr LIM:** Thank you.

**Mr DONNELLAN:** Thank you.

select COMMITTEE **ON EUTHANASIA**

**KATHERINE**

**PUBLIC HEARINGS**

Wednesday 5 April 1995 Opened: 15.30 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Laura-Lea BRUNNER

Ms Penelope Ann POUNDER

Mr John Duncan ROBERTS

Mr Nathan Ronald PARKER

Ms Carolyn Anna-Maree GOODE

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** I welcome Ian Roberts, Penelope Pounder, Carolyn Goodie, Laura-Lea Brunner and Nathan Parker, who are appearing as witnesses to give evidence. I think you all heard what I said before about telling the truth. I will not go through all that again. Is there anything that you are likely to say that you want to be kept confidential?

**Ms BRUNNER:** No.

**Mr POOLE:** All right. I will throw it open to you and we can then ask you some questions . I have set a time limit of about 30 minutes, all right?

**Ms BRUNNER:** Yes. Sorry, what do I have to do?

**Mr POOLE:** When you start to speak, you might just mention your name. All right?

**Ms BRUNNER:** My name is Laura-Lea Brunner. To start off with, I think that people should be more informed before the decision is made. The man who spoke before mentioned that we should have a referendum. People cannot really decide whether they are for or against it if they cannot make informed decisions. Either way, you are going to have to let people know more about it. It definitely needs to have more definitions defined so that it is more clearly set out and people can understand it a bit better. The question that you could ask is: 'When can people take their lives? At what stage of when you are terminally ill can you actually take your own life?'

I agree with some aspects of the euthanasia bill but it still has some things against it. I agree that families suffer a lot watching someone they love die. The financial side, for people who cannot afford it or who have family left behind, is hard on them too.

It seems that a lot of people do not understand that the euthanasia bill is for anyone 18 years and older, not just elderly people. A lot of people are sort of closing it in on that and saying that it is only terminally ill people who are going to be affected whereas it is actually all age groups above 18. So that is another one.

A question we wanted to ask was how the Territory would be affected if federal legislation was passed. It would only effect the states. Given that we do not have state powers and we are still federally governed, how would it apply the Territory?

**Mr POOLE:** Basically any federal law applies to the Northern Territory. All states and territories normally pass complementary legislation to federal acts. But in some cases, it depends on the actual act. For example, the Mabo Act applies to the Northern Territory but the Northern Territory Land Rights Act does not apply to the states. If a law is initiated by the federal government, it is normally a duty of the state or territory government to pass enabling legislation to cover that legislation. So if there was a federal law on euthanasia, it would apply in the Northern Territory and they would expect us to pass enabling legislation.

**Ms BRUNNER:** All right. Does anyone else want to say anything?

---

**Mr POOLE:** We might get you to write our report, I think. Almost all the things that you have identified so far are the questions we have already asked of ourselves, particularly about the time as to when people actually carry it out after signing the bit of paper. You are right about the emphasis being placed on the elderly. Of course, it is not a bill that strictly applies to the elderly. I guess, however, that more old people would be affected by the legislation. It certainly applies to 18year olds though.

**Ms BRUNNER:** Definitely. Is there anything else? Well, if the euthanasia bill is passed, you could ask the question: 'When is murder actually murder?' I mean, sometimes you really do not know if it is murder or giving someone mercy. That is another thing.

**Mr POOLE:** One of the intentions of the bill, I presume, is to clearly interpret the ability of a person to hold up their hand and say: 'I would like to be euthanased'. That is distinct from what some would call a grey area whereby doctors administer drugs and pain relief management to such an extent that, at the end of the day, the dosage is so high that the patient sometimes passes away. The argument there, of course, is that it was never the intent to kill the patient. The intention is to fix the pain problems.

**Ms BRUNNER:** A few other students have been asking whether the parliament is capable of handling such a controversial issue when issues such as abortion have not been cleared up yet. It basically has some similar issues.

**Mr POOLE:** Well, it has been. We have a law in the Northern Territory that permits abortion. It was passed about 8 years ago ...

**Dr LIM:** In 1986.

**Mr POOLE:** It was around then, before I got in. I think it was 1984. A law was passed to permit abortion in certain circumstances in the Northern Territory.

With regard to whether the Northern Territory parliament is capable of deciding such a thing, the answer is yes. The Northern Territory parliament can decide anything. I guess if the people think it is not mature enough, they will change the parliament and the members.

It is an argument that is often used when we do things in the Northern Territory, particularly by the federal governments although not necessarily this particular federal government. Other governments use it as well. They say: 'Oh well, they are just a little parliament; they should not be deciding things like that'. Quite often, United Nations charters suggest that we are too small to be deciding things like that. We believe that we have the right to govern on behalf of Territory citizens, who are no different to citizens anywhere else. Everybody else elects their governments. You elect your government. If you do not like your government, you kick them out and elect somebody else.

**Ms BRUNNER:** Right.

---

**Dr LIM:** Let me put a question for any of you to answer. Are discussions about this bill damaging the patientdoctor relationship? Suppose that I have been your doctor for the last 10 years and you know that I will perform euthanasia. You suffer a very serious illness, not necessarily terminal, but a very serious illness. If you came to see me as a patient, would it concern you that I practise euthanasia, and that maybe I will work very hard to save you or maybe I will not work so hard? Would that be a cause of concern?

**Mr POOLE:** If I was Perry Mason, I would call that a leading question.

**Dr LIM:** Of course it is a leading question.

**Ms BRUNNER:** Well, not really.

**Dr LIM:** But I would like to know how you think about it.

**Ms BRUNNER:** Not really. If that it is a family doctor or something, you place all your trust in that doctor. You know that he will be doing the best that he can for you. That is the reason why you go to him in the first place. If you are not happy with that doctor, you just go to someone else.

**Mr POOLE:** I suspect that is not the answer the doctor is looking for.

**Dr LIM:** I expected it, Mr Chairman. I asked my question and I expected the young people to answer as they wished.

**Mr STIRLING:** Good on you, Richard.

**Mrs BRAHAM:** Can I put a hypothetical question to you, or it might not be hypothetical. You are at the age when you are probably making decisions for yourself far more than when you were smaller. You are probably doing things like deciding what you are going to wear today, what time you are going to bed and who you are going out with. You will even decide, when you go to the polls, who you are going to vote for. You will not ask your mum and dad who they will vote for; you will probably make up your own mind. So, you are exercising your individual rights and growing into that era when you will do that in many ways. You will decide whether you will drive a car, whether you will drink alcohol, whether you will take drugs, whether you will marry and so on.

The arguments we often have with this bill are about choice. If you do not want to exercise the rights which this bill would give, then you do not have to. But why should you deny other people, who want to have a choice, to have that choice through having the bill passed? How do you see that question of individual rights?

**Mr POOLE:** As chairman, I reserve my right before you answer that question. You have been asked whether you support the idea of freedom of choice but you should also be aware of the other side of the equation. It is very much the case that governments sometimes

---

do not pass bills simply because they are popular. Capital punishment is a good example. The majority of Australians support capital punishment. The reason you do not have capital punishment in Australia is basically because of the moral and ethical arguments.

If we did have capital punishment, people like Lindy Chamberlain would not be here. When she was found guilty of murder, she would have been executed. Yet now she has been cleared by the legal process of the country. So I believe that we do not have capital punishment for that reason. Whilst politicians say that they would like to pass it because they know everybody wants it, they take the moral line and say: 'We are not infallible. As human beings, we can make mistakes. We are not going to pass that law because occasionally somebody might slip through the legal system and actually be incorrectly punished for something that they did not do'.

So there is a moral and ethical argument that, if you make a decision on freedom of choice, you also affect other people in the community. That is the real question, whether you agree to make a decision on your own rights or whether you agree to make a decision that affects the rest of the community as well.

**Mrs BRAHAM:** I will accept your interpretation.

**Ms POUNDER:** I would just like to say that I do think that this bill should go through. I support it because a family member and a very good friend of mine died of cancer. They just went through so much pain. Also, sometimes medical treatment cannot cure the pain but gets to the extent where you cannot be cured. At the time, there is no medicine that can stop the pain.

In the case of my friend who died of cancer, he just got so much chemotherapy pumped into him that it just made him sicker and sicker. They believed that it caused his death sort of induced it but it just made him go through so much pain. Without this, he might have lived a bit longer but he still would have been in a lot of pain. I feel that it is a person's choice to have this and to be able to die if they want to and if they are in so much pain that they feel they are not going to be able to survive.

On the other hand, there is an opinion that: 'Maybe I will survive through this and come out well in the end'. At the time, it is really hard because you are not sure if you are going to come through it or not. You would just be waiting and waiting until a time when you are either going to die or not. If you do not want to go down that path, I think it is your choice. Fair enough, you cannot reverse that choice once it is done but I think it should be your choice.

**Mr POOLE:** Are there any other views on that?

**Mr ROBERTS:** My name is Ian Roberts. I just agree with what Penny said. In a cancerous state, where it is past the time of treatment and any other sources of medical, spiritual or other ways of healing, there is a chance of going into remission. Then again, you do not know how long your remission is going to last. You do not know if you are going to develop any secondary side effects from chemotherapy.

Really, euthanasia has a lot do to with personal, moral and spiritual beliefs. A lot of people, especially young people, are saying: 'Yes, it is a great idea'. The older people, who you tend to look up to more, say: 'Well, no. It is not really good'. You cannot really second guess their kind of situation because they are older and wiser. A lot of younger people just end up believing what older people have to say. However, if we can get in quick enough and have our say as a younger generation, we might be able to have some bearing on the issues at hand.

**Mr POOLE:** So are you supporting the bill?

**Mr ROBERTS:** I am supporting it, yes.

**Mr POOLE:** Do you think many people of your age actually are aware of this bill and the discussion relating to it?

**Mr ROBERTS:** I believe many schools around the Northern Territory are discussing political issues at this stage and are very aware of the euthanasia bill. A lot of other states in Australia are aware of it. It is therefore filtering down to the younger generation having a say.

**Ms GOODIE:** I am Carol Goodie. I also support the bill because it does give you the option. You can choose euthanasia or you cannot. If it is there, you have the choice. If it is not there, it makes it harder for people who have a really serious illness or something. They do not have a choice. It is their life, so they should be able to make the decision for themselves, given all the facts.

**Mr POOLE:** Go on. Put your name on the record.

**Mr PARKER:** I am Nathan Parker. It is such a controversial issue. It is hard to make a decision on a personal basis. The community will pass a judgment which will effect the whole community. It is really hard to make a decision with the information that is around. It is such a hard decision to make. If the bill is passed, it will affect so many people.

**Mr POOLE:** You are basically saying that you are sitting on the fence or you would vote no.

**Mr PARKER:** That is right. I am not necessarily saying no but I will make my decision when I have more information about what is going to happen and how it is going to affect people in the future.

**Mr POOLE:** Right. Is there anything further you would like to say?

**Ms BRUNNER:** I would like to say that I think it should be passed after being refined a little bit. Dying with dignity, or euthanasia, is better than having someone who is terminally ill committing suicide because they just cannot take it any more. I think it is a more humane way of doing things.

---

**Mr POOLE:** Are there any questions from the panel?

**Mr STIRLING:** I think Laura made the point about the level of information out there and just how informed people are about the bill. I is one of the concerns I had when people talked about a referendum. On the surface, it seems very easy when people look at it from the point of view: 'Are you in favour of people suffering a painful death?' No one is in favour of that and you get a very high response rate.

I think there are other issues to be considered in the debate, and that those will not be covered by a simple yes or no question on a referendum. Mr Donnellan made the point quite clearly about the level of information out there. It is a question mark I have about the whole process and the need for the haste to have it enacted into law or defeated by May, when there clearly ought not be any haste at all. A 12month process would allow people to get across all of the arguments and have the information before them in order to make a much more informed decision. It is a good point and I commend you for it.

**Ms BRUNNER:** It is very difficult to get information. We are doing it for a major assignment and, for us to get the information that we need, we have to go through people who have to get it from other people. If you do not know where to look for it, it is not really there.

**Mr POOLE:** We have had about 1100 submissions do date, so you will be able to spend many happy evenings reading the report when it comes out ...

**Ms BRUNNER:** Thank you.

**Mr POOLE:** ... and writing many assignments on it.

**Ms BRUNNER:** Thank you. Thanks a lot.

**Mr POOLE:** I thank you for appearing. It has been very interesting.

**Mrs BRAHAM:** Thank you for your input.

select COMMITTEE **ON EUTHANASIA**

**YIRRKALA DHANBUL ASSOCIATION INC**

**PUBLIC HEARINGS**

Thursday 6 April 1995 Opened: 10.30 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives:

Mr Wanyubi Marika - Chairperson

Mr Djuwalpi Marika - Town Clerk

Mr Waninya Marika

Mr Yalpi Yunupingu

Mr Wali Wunungmurra - CEDP Coordinator

and representing Lanyhupuy Homelands Association

Ms Gundimulk Marawili

Ms Dhuwarrwarr Marika

Ms Natiti Marika

Ms Raymattja Marika

Ms Barbara Philp

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

**Mr POOLE:** The best thing to do is for me to explain what we are doing first up, and then we can talk about this euthanasia thing.

**Mr D MARIKA:** First of all, Mr Chairman, I would like to welcome you on behalf of the council and the chairperson, Wanyubi. [Inaudible] make apologies, they attended a meeting this morning. It is a great opportunity to have a discussion on this table about this matter, which has effect seriously for the whole community, not only to council members. [Inaudible] we would like to see this meeting meaning that we not take decisions today, but we want to solve it in the long run.

**Mr POOLE:** Well, I thank you for your welcome. We are very pleased that you were able to find the time to talk to us this morning, especially as I am sure you have your own important business to attend to. We appreciate your meeting with us.

We are a committee of the parliament of the Northern Territory: Richard, Syd, Maurice and myself and Loraine Braham, who sends her apologies. She had another meeting to go to in Darwin, so she could not come through to Nhulunbuy and Yirrkala today. The parliament has asked us to go around and to talk to people in the Northern Territory, all the people in the Northern Territory, anybody that wants to talk to us about euthanasia.

This euthanasia bill has been put to the parliament by Marshall Perron, but it is not a government bill. It is what we call a private member's bill, just like at your council meetings, if somebody wants to come and talk as an individual, not representing the community, all right?

He has written it all out it is here to help people who are very, very sick and are dying and have a lot of pain, like somebody who has cancer. The doctors have looked at them and said: 'We are sorry, but there is nothing more we can do for you. Unfortunately you are going to die, maybe in 2 weeks, maybe 6 months'. There is no cure, medicinewise, for you. When the pain gets so bad, you can ask the doctor to help you to put you to sleep. You don't wake up. Basically it is to kill. And it is not to kill a little bit, it is to kill stone dead.

So, when the person asks the doctor, the doctor has to go and talk to another doctor. So it involves 2 doctors and they both must examine the person and agree that there is nothing more that can be done for them, and agree that they're going to have a lot of pain, a lot of suffering, and maybe it would be better for them to go to sleep. But the only person that can do it is the ill person, nobody else.

Now, we have already spoken to some Aboriginal people in Central Australia. Of course, it might be the way for Balandas, but it is not the way for Aboriginal people. Aboriginal people tell us that has to be a family decision, everybody has to talk about it, all right? But this bill is not for families, it is for individuals, for one person to say to the doctor, all right?

In the white people, the Balanda, some people say good idea, lots of people say bad idea. So there is big talking and big arguments going on. This committee has to listen to what

you want to say, then we go back to the parliament. We are recording on the Hansard, so everything will be written down just like your letter and will be given to all the other members of parliament, so they all see what you have to say about it. So when the time comes, when they vote yes or no in the parliament, everybody understands the different points of view of all the different people the Aboriginal people, the white people, the Roman Catholics, the Anglicans, the nonreligious people everybody understands what people say about it, okay?

We are not going to go away today and say the people at Yirrkala think it is a good thing or think it is a bad thing. All we are going to do is say: 'This is what they tell us, you read about it.' Okay?. We are not really here to talk to you, like the usual meeting. We are here to listen to what you want us to tell them, okay?

I read your letter here. I think there is a pretty strong message there, that one of the problems we have is everything is too much of a hurryup. You know, we have to go back on 16 May, we have to give our report to the parliament, and about 26 May they are going to be talking about it and maybe voting on it.

I am happy to take any messages from all the groups that are represented here today not just from Yirrkala, of course, but from the other Homelands Association etc. So please, you tell us what you would like us to tell the parliament.

**Mr W MARIKA:** [*Language.*]

**Mr D MARIKA:** [Inaudible] like to ask [inaudible] question. How do you see this new bill Marshall Perron is trying to put from your areas, government?

**Mr STIRLING:** I have my views, Djuwalpi, but as part of the committee it is my job here today to listen to what your views are and the people that are here. So I do not think it is right for me to take up the time of this meeting with my views. I am happy to talk to you about my views outside of this meeting, but it is much more important for this committee to hear the views of the people here.

**Mr POOLE:** This bill is not a government bill. It may be hard to understand, but it is not the Chief Minister's bill, it is Marshall Perron, member for Fannie Bay, he make this bill. Now my party, the CLP Party, some people say good. Some people say no good. The ALP looks like some people say good, some people say no good. So, when we are voting, it is not ALP/CLP, everybody is going to vote individually, around the table, you know? It is not party politics.

**Dr LIM:** According to their conscience.

**Mr POOLE:** It is too important for ALP/CLP, and very important for you people and us as individuals a private thing, you know? Some people feel very strong, say it is a good idea. Other people say: 'No, no. It is against my religion, against my culture, against my ethics', whatever. So everybody is pretty divided on it, I think.

**Ms R MARIKA:** [*Language*.]

**Mr D MARIKA:** We do understand about Marshall Perron's frustration in his family situation, with his mother. He is trying to highlight those things to the public area with this, affecting all the communities, especially the Aborigine people through our culture. We want to see why he is doing that for blacks. It is breaching traditional things. We do not want to have that happen. Our old people have passed away. They have [inaudible] to maintain and respect that culture. We do not want to say, yes, we can do that. That is very hard for us.

I want to open this discussion now. Please, ask questions.

**Mr POOLE:** If Marshall Perron heard what you are saying, I think he would say to you: 'That is fine, because this bill, if it becomes the law, only applies if you want it. If you do not want it, you do not ask'. All right? But other people have said: 'Ah, but if you start like that, maybe somebody further down the track in 1996, 1997, is going to change it and say: 'You don't have to ask maybe the doctor just do it'.

That is one of the problems some of the people here have with the bill. But Marshall would say to you: 'Look, if it's against Aboriginal culture, that's okay, because you don't want it, you don't have it.' Not like a law for drink driving everybody is covered by that law. This one, only if you say: 'Please, help me. I want to go to sleep'. If you do not ask, then nothing happen, you know?

**Ms D MARIKA:** [Inaudible] yesterday, last night. But this issue, we have not actually contacted our community and explained to them. That is why we want to talk to you about how we feel. According to our law, people [inaudible] this area, our own people used to spear each other or kill or wound or any other [inaudible] used to take that person to a tribe, to gather all the family. That person, he knows that he is dying, and he meets all the family. So our culture, we put our dilly bags, arm bangles, all the sacred belongings of that person [inaudible] and he knows that he is dying. He wants the family to be there. That is our culture. We decided if any of our family who is absent from this community not just from here, from east to west let that patient come back to the family.

**Mr POOLE:** So it is very much a family thing, not an individual thing. It would cause lots of trouble if people say, 'Please help me', and they do not talk to the family.

**Ms D MARIKA:** If that patient is very ill, how can that person can talk to a doctor: 'Help me'?

**Mr POOLE:** No, that is one of the things in this bill. If the person is so sick, like maybe unconscious, the law not apply. Doctor cannot do it. Must be mentally competent, must be okay in the head to talk to the doctors, to 2 doctors, and ask for injection. But if too sick for that, that law does not apply.

---

**Ms D MARIKA:** [Inaudible], if that person is mental or very sick, let the doctor ring the family, see, and let the family go and talk to the doctor, and let that patient out from the hospital to ...

**Mr POOLE:** Come back home.

**Ms D MARIKA:** ... the community, yes.

**Mr POOLE:** I think we can take your letter here, this one you write, and put that in our report, because I think that is pretty strong message on what you feel, eh?

**Ms D MARIKA:** Yes.

**Mr D MARIKA:** [Inaudible] belatedly received We have a certain length of time for consultations, otherwise it would make it illegal. Can I leave them more explanation on that, on what you mean by that? We need to be properly consulted, as I was saying, in the community to give the proper message.

**Mr POOLE:** I think this committee would say to you that in the time we have got, we cannot properly consult. We can try. We are going to talk to maybe 50, 100 Aboriginal people, not more than that, because we must report to the parliament on 16 May. The message we are getting so far from you people here and the people in Central Australia is the same message that Aboriginal people do not like it. If we talk to 1000 people, I think maybe we get the same message.

**Mr D MARIKA:** I think you get from this area, Yirrkala, if you want to make answer now, I can give to you, because as you say you do not have time to consult. Our response is, we do not like this

**Mr POOLE:** Sure, I know that.

**Mr D MARIKA:** We have our own ideas of solving this [inaudible] by bringing the person back home and using cultural ways, ceremony, you know? I know that person will die, but we have a certain thing [inaudible] dilly bag, [inaudible] to put it on, and he knows that he will die. Same time, the earth knows. Mother Earth knows about it that he is going to die, he is going back to her. That is one of the significances, and we do not like to break that.

**Mr W MARIKA:** I have a question about young people dying, [inaudible] under age. How do you explain about all those problems?

**Mr POOLE:** In this bill there is the provision, must be over 18. It does not apply to people under 18. They cannot make that decision for themselves, all right? The important thing, I think, whether or not the bill gets passed, whether the parliament says it is a good bill or a bad bill, the important thing is that the way the bill is written, if you do not want it, it is not going to change anything.

---

**Ms R MARIKA:** That bill was written by an individual for individual people, to work for everybody. But we do not ...

**Mr POOLE:** If Marshall Perron was sitting here he would say: 'Look, if you don't want it, that's fine, because it will not apply to you'.

**Ms R MARIKA:** We do not want it legalised, because some people out there or here are against that.

**Mr WUNUNGMURRA:** [Inaudible.] They just cannot make decisions by saying, 'Yes, go ahead and do what you have to do', because if they did that, there are other people watching that family too. And they will say: 'Okay, we will fight them, then'. They will be blamed very much. So will the doctor that [inaudible].

**Mr POOLE:** Yes, they told us that in Central Australia. Gus Williams at Hermannsburg, he said could be payback among families, payback for the doctor, whatever.

**Mr WUNUNGMURRA:** All in all, it is principally wrong, okay? Ethically, culturally and morally, traditionally, it is wrong as far as Aboriginal people are concerned. It is wrong. The only way to go past it, it has to assist them. If the doctors cannot do anything about a sick person, then they have got to return that person to the community.

**Mr STIRLING:** I think it could not be any more wrong, Wali, from what you just said. I think you covered every point from which an Aboriginal person would see it, in principle, ethically, traditionally, culturally, morally, it is wrong.

**Mr D MARIKA:** One thing that really interests me is this Morgan poll. They want to say a lot of nurses throughout the federation are saying that it is a good thing, they support your idea. Fair enough. But we have two different kinds of people living in Australia, okay? One is Aboriginal, one is white, Balanda, eh? And these people have different ways of living. Whether you want to keep this idea like that man Hitler ... If you want to be a Hitler, Marshall Perron, you got to be careful. This is Australia.

**Mr POOLE:** I think maybe you are being a little bit unfair to compare him with Hitler. He is not trying to introduce the bill to kill people. He is trying to introduce the bill, from what he sees in the Balanda way, to help people who are so sick. Richard is a doctor. He would tell you a lot of people ...

**Ms R MARIKA:** [*Language.*]

**Mr POOLE: ...** a lot of people, you can give injections of morphine or something, some medicine, to stop the pain. But a few people you can do nothing for, and the pain is just terrible.

**Ms R MARIKA:** But we live with that pain. That pain is terrible, we really feel that pain ...

**Mr POOLE:** But some Balanda would say ...

**Ms R MARIKA:** That is for Balanda who cannot stand the pain, so they can use that way.

**Mr POOLE:** That is right. In a case like that, of course, it would only apply to people who want it.

**Ms R MARIKA:** To the person that wants that bill.

**Ms D MARIKA:** [Inaudible] his or her family, he does not want to see that person suffering. What we have to do is decided by our tradition.

**Mr POOLE:** But lots of Balanda say what you are saying. There are many Balanda, a lot of Roman Catholic Balanda, who say: 'No, no. It is morally, ethically, culturally, religiously very wrong'. So do not think all the white people think it is a good idea, because many people do not.

**Mr D MARIKA:** Pain is very important in our life. Cultural things, like we learn through pain, to experience it. For example, initiation ceremony for a little boy, we use [inaudible], sit up, using the doctor to relax him, stop the pain. That pain get something in our life that is very important, to learn through pain, experience that pain.

**Mr POOLE:** We have had white people say the same thing, that part of the process of dying is the experience of pain.

**Mr D MARIKA:** Can I just say, it is very interesting about this [inaudible] word euthanasia a foreign language that [inaudible] used in Australia. It has come from the Greek, what I understand. It is just a word that comes in our study course [inaudible]. Where it come from, where the hell it come from? 'Eu' could mean Greek word 'good' and 'thanatos' mean death. I do not know where the word Marshall Perron [inaudible], I do not know, the white ...

**Mr POOLE:** No, it is a common word in English language. This same subject has been discussed in many countries throughout the world. But so far, the only country that has a law like this is Holland in Europe. They have this law. They have it also in one of the states in the United States, in Oregon, but they do not do it because there is a challenge in their Supreme Court to stop that law being implemented. So there is not only argument in the Northern Territory and Australia, there are big arguments in Europe and America about this law. It is not only Marshall Perron. There are other governments. Right now Tasmania, South Australia and the Australian Capital Territory are all talking about bringing in the same law. So there is a lot of talking about it.

**Mr WUNUNGMURRA:** Just a question, excuse me. [*Language.*]

[*Language between witnesses.*]

7

---

**Mr D MARIKA:** People who suffer with AIDS, how would they be covered in this category?

**Mr POOLE:** AIDS groups are supporting the bill, because ...

**Mr D MARIKA:** They're supporting it?

**Mr POOLE:** Yes, because when you die of AIDS you can have a very horrible death, a very painful death, and it can take you a long time. So they see it as a good idea. But, to be honest, I am sure if you talk to all the people involved in AIDS, some people would say it is good and some people would say it is bad. I do not think there would be total agreement.

See, one of the things the white people, the Balanda old people, are scared of is that governments would start to use it because it is cheaper than looking after old people. We have had some old people come to us and say: 'No, we don't like this, because the government's going to change it from asking, 'Please help me', to saying, 'Oh, you're sick, you're old, you best go to sleep', and give them injections. Some people are scared about it.

**Mr D MARIKA:** What about the economic side, like where is the money, say? Government does not want to use too much money. Surely that is one of the other things.

**Mr WUNUNGMURRA:** Just wandering around our communities you have been down south in Central Australia you all know that the traditional lifestyle and cultural lifestyle of the people of the Northern Territory alone is very much alive and well. And that is why this is very, as I said, principally wrong. [Inaudible.] Might be for that traditional culture and traditional life [inaudible] but for life, the rest of my life. So to take a life away from that particular person who is suffering from [inaudible] and pain [inaudible] stealing something from them, something precious.

**Mr POOLE:** It is probably different up here, but we were talking to some people down south in Central Australia and they talked about a long time ago. Aboriginal people in the desert country were always moving, always hunting, just to stay alive, following animals around the desert because there was not a lot of food. If somebody got very sick or fell down a riverbank and broke their leg or something, could not stay with the family group, they used to leave them in the desert by themselves, and carry on. A long time ago. Have you ever heard any stories like that?

**Mr WUNUNGMURRA:** They would carry them. [Inaudible] travel a bit slower.

**Mr POOLE:** Because that in itself is a type of euthanasia. Not the same thing, but same principle, for the good of the community. If they all stayed with the person, maybe they would all die, because they would run out of water and they would not have any food. So they would have to leave them.

8

---

**Mr WUNUNGMURRA:** We have nothing like that [inaudible]. We have not heard anything.

**Mr POOLE:** That is because you have so much food up here, lots of food and lots of water. And I am not saying that happens now, I am talking long time ago.

**Mr STIRLING:** In your letter, it says the land knows when a person is going to die. Does the person also know?

**Various witnesses:** He always knows ... He knows that the land wants him ... He knows that he is dying.

**Mr POOLE:** So they see the signs.

**Ms D MARIKA:** The signs, yes.

**Mr STIRLING:** And wants to come home, or must come home?

**Mr WUNUNGMURRA:** Signs. They want to.

**Mr D MARIKA:** [Inaudible] Aboriginal people have 2 lives. We have a physical life and a spiritual life. In the spiritual life, that is what it tells us, that the body needs to go back to Mother Earth, and that is what the signs say, instead of you and I getting hurryup and getting injection to finish us up. It is already [inaudible] to that.

**Mr POOLE:** All right. Well, I think we got the message, pretty clear.

**Mr STIRLING:** I do not think it could be clearer than what Wali said.

**Mr WUNUNGMURRA:** What did I say?

**Mr STIRLING:** It is very wrong.

**Ms R MARIKA:** Some people are getting scared if they are in hospital ...

**Mr POOLE:** There is no need to be scared because ...

**Ms R MARIKA:** Especially old people.

**Mr POOLE:** Yes, but even if the bill got passed, we will make sure that the parliament hears your message very strongly. Even if the bill got passed, it should not affect old people going to hospital, because they have to say, 'Please kill me', you know. And there is a system. They must sign a paper and have an interpreter and all that stuff.

**Mr WUNUNGMURRA:** A relative can sign.

---

**Mr POOLE:** Nobody else can sign for you.

**Mr WUNUNGMURRA:** Excuse me, the relative that normally stays with this particular person who is very, very sick, one of their business to the sick person is to comfort him [inaudible] make things better [inaudible] from this earth to another life [inaudible] but spiritual [inaudible] another world, is to participate in that journey of a very sick person. Because [inaudible] taught to believe that person, after he or she has been sick for a long time, tends to be taken away. They are no longer being here. During the time when they are sick is the time for them to be able to make this break [inaudible] they will take. So we, the people who are sitting there to comfort them, [inaudible] support them and help them to cross that [inaudible]. So that is why we would like doctors, if they think that they cannot do anything about the sick person, then it is better for them to return the patient to the community.

**Ms D MARIKA:** But these people at least let the person go by spirit [inaudible].

**Mr D MARIKA:** I think it is modern medicine, Balanda medicine. We never even practised [*language*], black magic, and if something [inaudible] try that, Balanda people are going to try that.

**Mr POOLE:** Well, some of these Chinamen do that.

**Dr LIM:** I come from Alice Springs, and I have worked in the hospital in Alice Springs. I have looked after a lot of Aboriginal patients there. I also work in the intensive care unit. Sometimes, when we say to the family: 'Your mother, she's very old, she's going to die soon. Are you going to take her home?', they say, 'No, we don't want her to come home, because if she comes home, then we have to go through sorry business, we have to smoke the house and all that. We want her to die in hospital or a nursing home'. Now that happens in Central Australia. Does it happen here in the north?

**Mr YUNUPINGU:** No.

**Mr POOLE:** No, but maybe it could in Darwin Hospital. If the hospital cannot do anything more, do they usually send the person home? Would they bring them back here? Sometimes it is ...

**Dr LIM:** In Central Australia sometimes it does not happen. Sometimes they say: 'No, no. You keep the person in hospital'.

**Mr D MARIKA:** We only do those things when we have lost our culture. But we have strong culture. We want that person to come back.

**Ms R MARIKA:** We look after our old people [inaudible]. Balanda people put the old people in homes, but we still look after ours.

---

**Mr POOLE:** Why Richard asked that, if you ask some of the Aboriginal people in Central Australia about that, they say they want them to come back home. But we know it not always true. Some people tell the hospital: 'We don't want them to come home. We want them to die in the hospital'.

**Mr D MARIKA:** [Inaudible] trying to push this customary law. We want to bring the rule of law to the white man so he can document it. [Inaudible.] We send the book so you can read it. That's been going for a long time. We want to push that thing. Then you can respect, as we respect your culture.

**Mr STIRLING:** Have there ever been times when a Yolngu person, who is old and ill and approaching the end of their life in hospital, wants to come home, the family wants them to come home, and the Health Department say no? It never happens? They always have them come home? If the person was very old and ill and wanted to come home, has there ever been a case where the Health Department did not let that person go, and say: 'No, that person's too sick, they need treatment', or 'They need to stay in hospital'?

**Mr WUNUNGMURRA:** I have known older people who have run away of their own accord from the hospital, especially the older ones. Even though the doctors want to tell them to stay for a few more days, they have decided to walk away. It has not been the doctors or the nurses or people working in the hospital refusing to let them go. It has always been the patients themselves that want to go home.

**Dr LIM:** The law is that the hospital or doctors and nurses cannot stop someone from leaving. They can always go themselves, though sometimes they are asked to sign a form. They say, 'I want to go, let me go', and that's it. They can do that. The official term is taking their own leave from the hospital.

**Mr D MARIKA:** When someone dies in Darwin and the family want the body back, sometimes it is the wrong body. That is why we want a sick person to come back, so if something happens to him, we know it. One stage, we had [inaudible] experience. We had the wrong body. Some people had to cry and that, for some mistake person!

**Mr POOLE:** It has happened to Balandas, too, sometimes. They get them mixed up and one goes that way and one goes that way. It is not good. Not very often that happen though, eh? How many times that happen here?

**Mr D MARIKA:** Several times.

**Mr POOLE:** Several times? What, 3, 4, 10?

**Mr YUNUPINGU:** Maybe 10.

**Mr POOLE:** What, just a mixup because they don't understand the names or something? A lot of people have the same surnames.

---

**Mr STIRLING:** Or very close names.

**Mr POOLE:** Not good. All right. Okay, thank you very much.

**Mr D MARIKA:** Thank you very much.

**Mr POOLE:** Mr Chairman, thank you for finding the time today, because I know you are very busy. Thank you.

select COMMITTEE **ON EUTHANASIA**

**NHULUNBUY**

**PUBLIC HEARINGS**

Thursday 6 April 1995 Opened: 14.10 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative: Aboriginal Resource and Development Services Inc.

Mr Howard Amery, Community Educator

**Note:** This is an edited transcript.

**Issued: Wednesday 26 April 1995**

---

**Mr POOLE:** I call to order this hearing of the Select Committee on Euthanasia on Thursday 6 April 1995 and welcome the following witness on behalf of Aboriginal Resource and Development Services Inc., Mr Howard Amery, Community Educator, who is appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before the committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to the committee should be truthful.

Witnesses do have the right to request that their evidence be taken in camera or remain confidential, as the committee has authorised for the purposes of this inquiry that the usual proscription on the publication of material placed before the committee by witnesses does not apply. So if you wish to give evidence in camera or make it confidential, it is up to you. Do you wish to do that?

**Mr AMERY:** I am happy for it to be open.

**Mr POOLE:** Okay, fine**.** For the Hansard record, please state your full name and the capacity in which you are here today.

**Mr AMERY:** Howard Clive Amery, Community Educator with Aboriginal Resource and Development Services. I am based here in Nhulunbuy and work in the East Arnhem region.

**Mr POOLE:** Welcome, Howard. In the hearings we have had coming up the track, we have allowed the people to talk to their submission or make their submission or read from their submission, and then if need be we go into a questionandanswer session. Are you happy to do that?

**Mr AMERY:** Yes.

**Mr POOLE:** Okay, over to you.

**Mr AMERY:** I would like to talk to the submission. Do you want any more background on ARDS and the general work that we do, or just go straight into it?

**Mr POOLE:** Entirely up to you.

**Mr AMERY:** Okay. ARDS is part of the Northern Regional Council Congress, which is part of the Uniting Church of Australia. It was formed out of the Methodist Overseas Mission, so we have a long period of involvement with the people of the East Arnhem area. Our focus is on empowering people to regain control of their lives, both their individual lives and their corporate lives. That is the work of ARDS at the moment, our focus is in the East Arnhem region. We work with Aboriginal people in communities on a range of issues: health

---

range of different things as requested. We also work with government agencies and other organisations, working crossculturally, helping with the flow of information so that the agencies and the people can better hear each other. That is the capacity in which I have come today. Apologies from Richard Tudgren, who cannot be here today. He is in Darwin doing exactly that, within the legal system interpreting for a court hearing.

In regard to this particular issue, I will just share with you some of the things we have been hearing from the people in the East Arnhem region that is, from Milingimbi, Ramingining, Galiwinku, Gapuwiyak across to here. We have probably spoken to 20 or more Aboriginal people, or Yolngu, on this issue not to any great length but certainly sufficient to ascertain where their feelings and their perceptions are.

I guess the first thing to say would be that "bad news travels fast". Yolngu people do not know their rights at law. They still think they are under the welfare system, even though that ended 30 years ago. In their estimation a doctor, a very important person in a privileged position, has total power. If they are in Darwin at the hospital, for instance, and they abscond, then the police can be sent after them and are sent after them to bring them back. That just reconfirms to people that it is still "welfare". They have said they do not have the power and do not have the choice of whether to say yes or no about the sorts of medical treatment that they might get.

The area of communication is obviously a very difficult area. People do not understand what is being told to them or asked of them within their treatment context. The tendency is for people to say yes to everything, because the questions are often closed questions requiring yesorno answers. People usually say yes, wanting a conversation to keep going or not wanting to appear ignorant, for many different reasons. But clearly they are not understanding what is being said to them, because it is the second, third, sometimes even up to the sixth language for people. It is a foreign language.

Some people think that a doctor already has the power to kill. If they definitely know that doctors do have this power, then I think that has some fairly big implications. The whole process of this issue being raised up in the media, people hearing bits and pieces of it, not the full story, as it goes on it really serves to reinforce to people: 'Gee, it's what we thought they actually have that power'. If the bill went through in its current form, they would then know that doctors do have that power. That is the news that they would hear first: doctors have the power to kill.

The implications of that are fairly large as far as Aboriginal health is concerned. People are already scared of going to the clinic, fronting up for things like routine injections. They would be even more petrified. They would be petrified of all injections if they found out that doctors can kill by that means. Consequently there would be a much lower compliance rate.

Perhaps it might be helpful to the Committee if I put forward several case histories to illustrate that. A senior health worker within the East Arnhem region, a person who is in charge of a clinic where there are 5 or 6 other Yolngu health workers and a doctor present, was unable to get her own mother, who was critically ill, to come to the clinic to see the doctor. And it was not a visiting doctor that doctor was resident within the community. It was only after an ARDS worker intervened and talked with the woman in language and explained to her, using the culturally appropriate concepts, that the woman was able to find out that she had 2 nameable sicknesses. She then felt able to come to the clinic, fly out to hospital for some initial treatment, then come back to the community and die a peaceful death with her own people.

A second case is an old woman at her homeland within this immediate Gove region. Her daughter wanted her to come to the hospital and get treatment, but she told her daughter it was better for her to die at the outstation in her own country, even though it would be quite painful to do so better to do that than to come into an alien and threatening environment where she did not understand what was being said, and what was being done, and why. Everything that happened in a hospital environment was completely foreign and alienating for her.

Case 3 is that of a Yolngu traditional healer or doctor who was in hospital suffering from stroke. This case was mentioned briefly in our submission. I would like to give you a more detailed runout of that so that you can appreciate the dynamics. An ARDS worker, one of our team, went to visit this man, whom he knew and had heard was in hospital. The interaction, which was conducted in his own dialect, went something like this:

B. 'Well, I have come to visit you. I heard that you were sick'.

Y. 'Have you got a Bible, by the way? You know, so that I can put it

under my pillow?'

B. 'Don't you know what your sickness is?'

Y. 'No'.

B. 'Haven't the doctors or nurses explained to you about your sickness?'

Y. 'No, they haven't told me anything'.

B. 'What are you thinking about your sickness?'

Y. 'Well, I am thinking that my arm is being played around with or

doctored by someone. It has turned into a snake. I have no feeling

in it. It is no longer part of my body, it just has a life of its own'.

As a traditional doctor he knows anatomy very well. He has treated lots of people for different complaints, doing things ranging from general massage to extraction of different poisons and whatever from the body. He is quite a skilful man, but he had never come across stroke before.

It was explained to him by the worker that it was a Balanda sickness, a whitefellow sickness, and there was some treatment for it. The worker offered to find a sister or a doctor and see what more they could tell him about the sickness. He found a sister and brought her back to the ward and asked, 'Have you explained to this person here about his sickness?' to which she replied, 'Yes, he knows about it'. 'How does he know?'. 'It has been explained to him through his son, who was with him and who speaks good English'. So his son had accompanied him to the hospital. He then asked the person in language: 'Did your son know the story about the sickness?'. 'No, he could not tell me anything about it. We both do not know what the story is, what sort of sickness I have'.

The worker then went off with the sister to get more background information, to research more about what stroke is and how it affects the body. (This is how we work, we learn as we go, we are not medical practitioners or lawyers or whatever, we do "research in process".) After spending a couple of hours away he came back and looked around for any suitable charts or pictures or things that might help to explain. He spent about 20 minutes interpreting for the sister and helping to explain what the sickness is, what causes it, how it affects the body, how smoking restricts the flow of blood through the arteries and through the capillaries in the brain, and how it can be treated.

At the end of that period just 20 minutes of dialogue in language, and a sort of communication with the sister the patient straightaway said in his own language, several times: 'I can see it, I can see it now. Now I understand what this sickness is and what I need to do to get strong again'. Straightaway he became very receptive to information from the sister, and very compliant. He saw smoking for the first time as his No 1 problem, and he was released to go home a few days later. About 5 days after seeing him in hospital, the worker was in that community doing some other work. He sat down with that person at his camp and was thanked several times for helping him. The Yolngu man called all his family together and explained how he and all the other members of his close family had given up smoking as soon as they heard the story.

From that, we believe that by this process of including of people, dialoguing it through with them, giving people information, they are empowered and have real choices to make about what they do or do not do with their lives. We cannot decide for them, they have to make the choices.

**Mr POOLE:** And the reason the son had not been able to help, while he was able to speak English quite well, he just was not literate in it?

**Dr LIM:** He did not understand the concepts.

**Mr AMERY:** Yes, he did not understand the concepts. He had good, everyday, expressional use of English. I think it highlights the very real problem of crosscultural communication difficulties that we have, the lack of adequate resourcing and adequate provision in that area for example, no interpreting services at all for a very large proportion of the Northern Territory population who speak English as a 2nd, 3rd or 4th language.

We say that Aboriginal people have a "naive" or sometimes a "magical" awareness of how our system works and how the Balanda get all the things they have, how these buildings spring up, and how instant towns just arise like Nhulunbuy. How does it happen, and where do they get the power from? But on the other side, it seems that government, or the dominant society, also has some of that same sort of natural thinking. For example, patient A arrives at a hospital feeling frightened, feeling alienated, not knowing what is going on, what he has come in for, what is going to happen, what that person is doing who is coming in and out. 5 days later, patient B arrives in the hospital and patient A, being from the same language group, is brought in and asked to interpret for patient B. Magically, just by being there and looking up at the ceiling, all of a sudden he imbibes all these concepts ...

**Mr POOLE:** The blind leading the blind.

**Mr AMERY:** And he can do it in 2 languages! That is good in 5 days. It is amazing!!

**Dr LIM:** I suppose osmosis help. It does help. Living in a culture and just talking generally, you absorb some of the culture just by observation. That is what it is. I suppose lying in a hospital bed, looking around, if you were there long enough you might understand it, but if you are only there for 5 days you might absorb the wrong information and have more problems.

**Mr AMERY:** You make lots of guesses. How many of those would be accurate, I am not so sure.

**Mr POOLE:** I have done your crosscultural course. I am very supportive of it.

**Mr AMERY**: I have another part which looks at how Yolngu people perceive death and dying. When a person is old and wanting to die, because they are suffering from a terminal illness or just because they are old, then that person as an individual is free to choose a form of voluntary euthanasia used in a natural way that is, they voluntarily give up eating or drinking and so hasten the onset of death. This is not done in isolation from the rest of the family, and from the family's feelings and thinking, and from whoever is the head of the family, clan, or tribe for that person within that particular context. It is done in consultation. Ultimately the decision is left up to the individual. If the individual takes that decision of voluntarily giving up eating and drinking, the other family members at that time would start to begin some of the mortuary rites and start to assist the whole process to happen.

**Mr POOLE:** If an individual said, 'Yes, I want to go down the path of euthanasia', and did qualify under the terms of the proposed bill, that would be highly disrespectful of the rest of his family, if he did it without discussing it with them.

**Mr AMERY:** It would be a very large diversion from what is normally accepted practice and understanding of just who am I within my social context, within the context of the universe. That is just not something that, in that traditional context, would arise.

**Mr POOLE:** We have some evidence given to us that in Central Australia there have been a number of cases where people just would not take terminally ill people back into the community. They move on from their outstation rather than pick up the phone and allow the hospital to make arrangements to get the person back into the community to die. And the reason given was that the sorry business was too complicated and smoking and having to move out of the house and all this sort of stuff. I might be a bit confused by it, because the Aboriginal people that we spoke to said, 'Oh, no, it would not happen', but certainly some I believe quite genuine people in the Health Department said there were a number of occasions when they had tried to arrange[inaudible].

**Mr AMERY:** I think probably the key issue is the degree to which people feel that they are or are not in control of their lives. If outside agencies have already taken control, instituted a whole series of proceedings, and then all of a sudden they do an aboutface and just say, 'Here it is back again', then people might say: 'Hang on, you have taken all the control and you have started the whole thing. Now you are dumping it back on us, not thinking about where we are at. We do not know what you have done.'

**Mr POOLE:** And I guess that does happen, particularly with cancer patients.

**Mr AMERY:** We can think of another instance, quite distant from this particular thing. I have gone with Aboriginal people to see the skeletal remains of people who died 40 or 50 years ago, down in the museum in Melbourne. One or two persons out of the group were willing to go in and have a look, only about two. The rest were really scared, really troubled. And when these two senior people went in and saw the particular condition that those bones were in, straightaway they said: 'We are not going to touch that. That has already been worked through to a certain stage. We now cannot even begin to enter into that process that has happened. We have not been given all of that story. We can guess and know fairly well where it is up to, but the person those bones were entrusted to knew the law and they have acted in a proper way. No, those bones are best left there. We do not want them back so we then have to re-process and do all of those things when we do not know the story'. It is the same sort of thing.

**Dr LIM:** Let me put a scenario to you. You have a tribal elder who has been diagnosed with cancer and gone through the process of assessment by the doctors and been given 12 months to live etc., etc. He fulfils all the terms of the bill. The doctor tells the patient to discuss it with his extended family in the best process possible. He says: 'Here is your choice, you stay in the hospital or you go home'. The choice is: 'I want to go home'. They go home and they go through the process of grieving, the mortuary process we have talked about. Could they, some time through that process, say: 'Doctor, could you come out here and do it for that man now? We have gone through the process. Please help him pass away peacefully by giving the injection'? Could that be part of the process of the whole thing, incorporating technology into the tribal process of grieving and dying?

**Mr AMERY:** I cannot imagine that happening. We have talked to people and heard them. Their words are 'in a natural way'. They would not perceive that as being in a natural

---

way. It is individual volition, individual choice. Any assistance, by an Aboriginal person or a nonAboriginal person, would be seen as murder. Who is guiding them? Who gave them the power to do that? How come they are giving the injection? Something else is happening another, bigger part of the picture. We say galka business (downward gesture of the hand). The doctor just becomes a pawn or a tool.

**Dr LIM:** Could the doctor not be the pawn or the tool of the family, rather than galka?

**Mr AMERY:** I do not think the family would choose that, because it is not perceived as natural. It is a very unnatural way. Suicide, for instance, is not a concept within traditional society. At the end of 1991, early 1992, there was a spate of about 4 suicides within a period of 6 months. It rocked the whole of East Arnhem Land. People virtually said: 'The world is being turned upside down. What is happening to our young people? We have never had this sort of experience before. This is something that is really new, really alien and really frightening. We do not know what is happening here, and we are really scared. Young people taking their lives because their boyfriend had jilted them or something'.

**Dr LIM:** Following up on the point Mr Poole raised, you have a patient who is very ill out in the bush and I come from Central Australia as well perhaps he has decided it is time to die. With the family support systems, the process starts. Halfway through the process, an Aboriginal health worker or even one of the more urbanised members of the family says: 'No, we cannot do this'. He brings the patient to the hospital in Alice Springs and says: 'Mum is very, very ill. Do something'. That has happened. I have witnessed it myself in a strict medical situation. On that request, you need to help the patient. So resuscitative procedures are commenced, intravenous drips, whatever. The person recovers to a stage where he says: 'Look, I want to go home'. That then comes back to Mr Poole's statement. The family says: 'No way, we will not have anything to do with it'. We have to see it from a Balanda point of view that a family member, hopefully with the support of the family, wants this to happen. Now suddenly they have abdicated all responsibility.

**Mr AMERY:** Perhaps I could share with you some of what I have experienced from living and working in the community in the East Arnhem area. Among people who are very traditional, if someone is sick and people are scared that they are going to die, there is no way in the world that they are going to let that person get on the plane. They will say: 'No, this person looks like they are going to die. They are staying right here'. If that person is a mature adult, they themselves will make that same decision: 'There is no way that I want to die outside of my area, my country. I want to die right here'.

The only time that people will be happy to let people go away and get treated is when they are assured that they are going to come back alive not in a coffin. They do not want to see them come back in a coffin. People from farther out in the East Arnhem area call the hospital up here 'the murder house'. What has happened is that sisters have come and said a baby or a child is sick and needs to go out for medical treatment. They die and come back in a coffin. People are very, very unhappy about that. While I accept the sorts of scenarios and situations that happen down in the central region, we do not see that sort of thing happening here.

**Mr RIOLI:** Do health workers think the same way, seeing some of their old people, sick people, in that position? Or do they think, because of the training that they have had, there may be a chance if the patient did go into hospital?

**Mr AMERY:** I think the health workers, being members of their communities, members of their clans, if they thought that there was any chance that a person was going to die and they were related to them in some way, there is no way they would say: 'It is better for you to go and get treatment. You might pull through, so better you go. And if you die, well at least we have done our best'. I do not think they would see it that way.

**Dr LIM:** The argument is that this bill only applies to those who want to exercise the privilege of the bill, if I can call it that. This morning we discussed it with a group of people and they said: 'Look, this is not for us. If Balanda people want it, it is their business. They can have it'. If that were the case, the passage of this bill to become a law in the strictest sense of the word is not across their culture or impacting on them. Do you see that at all?

**Mr AMERY:** How will you frame or develop that law?

**Dr LIM:** If they do not want it, they do not have to pick it at all.

**Mr AMERY:** But if doctors do have that power to kill, which is what ...

**Mr POOLE:** The bill is very much on request, whereby you say: 'Doctor, I am in such pain and suffering that I want to terminate my life'. It is very much on request. Then it has to be backed up by another doctor, who has to talk to the patient and agree they are terminally ill etc., etc.

**Mr AMERY:** The concerns that we would have are in the area of crosscultural communication or crosscultural miscommunication.

**Mr POOLE:** We said on day 1, no traditional Aboriginal person going into hospital would ever dare sign anything. Word would get round, whatever you do: 'Don't sign a piece of paper'.

**Mr AMERY:** They would be very fearful that they might be tricked into signing something, and the family would be very fearful ... 'That old man, he doesn't know. He can't read or write. They'll talk him into something and he will say yes, and before you know it ...'

**Mr STIRLING:** Just the first sight of a syringe, for treatment ...

**Mr POOLE:** Measles injection.

**Mr AMERY:** The point is that people are already fearful. Our perception is that the passing of such a bill will make people even more fearful and would be detrimental to Aboriginal people's health.

---

**Mr STIRLING:** It is just not true to say that it will not affect other people, that it only affects those who want it ...

**Mr AMERY:** As soon as it is made law, it is law for everyone. People still have to put their hand up, but the way that people put their hand up, with huge crosscultural difficulties in communication and the fact that other people can sign for you, I do not think that there are enough safeguards ...

**Dr LIM:** If the bill were not passed, is there any distrust still, or will that distrust disappear? The debate is happening now. Obviously there are a lot of concerns and worries. If people in East Arnhem hear that the bill failed, would that allay their anxiety?

**Mr AMERY:** I think the issue would have been heightened. The key then is in terms of the amount of dialogue and the opportunity that people had to hear the full story, all the information, in a language and in terms of concepts that they can understand. If they receive the information, I feel very confident that their fears would be allayed rather than heightened. But if they do not receive the full story, then the reverse can happen.

People are already fearful. What we are hoping is that we can get a better communication flow going to both parties. We will appreciate more about what Aboriginal people see in death and dying and other health issues. They would also appreciate the way that we are seeing those. Our experience is very clear: when they get the story, when they get the information, they become very compliant. We have had quite a lot of success.

But the Rights of the Terminally Ill Bill ... What are the rights of the terminally ill from a Yolngu perspective? I think they are probably similar in some respects, and very different in other respects, from Balanda. I have touched on some of those. The right to die in your own country is very strong. I have seen that in Western Australia, when I worked there in a largely deculturalised community. A person had been away from their country, in an old people's camp close to the town. As soon as that person, who was about 80, knew that it was the time that he was going to die, he went back to his community, took off his clothes and wandered out bush. Some family and friends went off and grabbed him and said: 'This silly old bloke is not in his right mind, let's take him back'. He went off and did the same thing again. He died out bush.

**Dr LIM:** I know of several instances in Alice Springs, and that is where the relatives and others pull them back.

**Mr AMERY:** So that is one of the rights of the terminally ill , or of old age. The right to earlier diagnosis of conditions which in their early stages are treatable again, communication is a key issue. I have seen people who have gone off to Adelaide from this central East Arnhem region, who have had cancer and received chemotherapy. They have come back and are still alive today, 10 years later. Provided they get the story and they know what it is about, then we can cross a whole heap of barriers to people.

**Mr POOLE:** Everybody happy?

---

**Dr LIM:** Can we have a copy of that as well?

**Mr AMERY:** Yes. Can I send them in to you?

**Mr POOLE**: Yes, no problem at all. All right, thank you very much for appearing today.

**Mr AMERY:** It is just dying naturally seems to be the key, 'in a natural way'. We call that voluntary euthanasia. Euthanasia is not the term that Aboriginal people are using, but if we look at the dictionary definition, then it is a "quiet and easy death", whereas the assisted euthanasia that we are talking about, Aboriginal people see that as murder or as sorcery business.

**Mr STIRLING:** We had a similar message at Yirrkala this morning. The message from Yirrkala seemed to be quite strong, as in: 'You leave this business to us. We have been handling this for quite a while now, and we know what we are doing. You go and do what you will do'.

**Mr POOLE:** The women's attitude apparently, after the meeting, was: 'It's up to you guys. If you want to have it for white people that's fine, as long as it doesn't affect us'. I think that was good. They are becoming more relaxed, and more knowledgeable about what we are actually talking about.

**Mr STIRLING:** I do not think we can say it is not going to affect other people. Therein lies a big problem. But thanks very much, Howard, for such terrific insight there.

**Mr AMERY:** I will certainly send a copy of that in to you.

**Dr LIM and Mr POOLE:** Thank you.

**Mr STIRLING:** Thanks for coming in.

select COMMITTEE **ON EUTHANASIA**

**NHULUNBUY**

**PUBLIC HEARINGS**

Thursday 6 April 1995 Opened: 14.55 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Mr Ivor Alexander

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** I welcome the following witness, Ivor Alexander. Did you hear what I said before with regard to giving evidence?

**Mr ALEXANDER:** No.

**Mr POOLE:** Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to the committee must be truthful.

I also advise that the committee has authorised, for the purposes of this inquiry, that the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that that their evidence be taken in camera and/or remain confidential. Could you advise us if that is the case? Are you happy to have printed all of what you say?

**Mr ALEXANDER:** Yes, happy with publication.

**Mr POOLE:** For the Hansard record, please state your full name and the capacity in which you appear today.

**Mr ALEXANDER:** My name is Ivor Alexander. I appear here as a private citizen, although I come from a background connected with this matter.

**Mr POOLE:** What we normally do is listen to what you have to say and then we can ask questions, either as we go along or when you finish speaking.

**Mr ALEXANDER:** Thank you. My background is in health care. I am a communicable disease officer, but I am not here representing any particular government department. I also am a member of the Northern Territory AIDS Council out of Darwin, mainly in relation to my role as an AIDS coordinator for AIDS/STDs in the East Arnhem district. I am also a member of the National AIDS Counsellors' Association, which is a federal body.

I would like to address the proposed bill as is, in 5 areas the first one historically, in that in most cultures the state owned its citizens body and soul. I was going to quote a story from a very ancient tradition, namely the Jewish people, in relation to an incident that took place in AD73 at a place called Masada some people may be aware of this situated on the west bank of the Dead Sea. The Romans were absolutely infuriated that the Jews had risen up against them, and about 960 people had inserted themselves into a fortress on the top of a mountain named Masada. The Romans moved against them and stormed the fort. They found that out of the 960 people who were there, only 2 women and 3 children remained alive. The people as a group had decided that rather than becoming slaves to the Romans, they would systematically and voluntarily kill each other by lot number draw, and then the remainder would commit suicide. The Romans were absolutely outraged at this, not because these people were dead they probably intended to slaughter them or enslave them themselves but because as far as the Romans were concerned they were total subjects of the state and should belong to Rome. They were not allowed to make their own decisions about whether they lived or died.

---

That certainty has gone, I believe, across most cultures, that citizens did belong to the state, body and soul. Suicide traditionally, at least in western culture, has been seen as a crime and now is not. Being accessary to suicide is, the story goes, a criminal offence. We have progressed on the matter a little bit. It is interesting to see that there is a now a power to refuse an autopsy by relatives. Once upon a time that would have been unheard of. If the State said autopsy, it had to happen. I believe in some cases now, in some states and territories, for some relatives, they can refuse them.

**Dr LIM:** Autopsies are asked for by the state authorities these days. Without being asked, you do not perform an autopsy.

**Mr ALEXANDER:** But that was not always so.

**Dr LIM:** As far as I know. I have been a practitioner for 25 years.

**Mr ALEXANDER:** Sorry, I am going back further than that, where people had no right with the deceased person until the state was finished with them and handed them over for burial. So suicide was seen as quite horrendous, not just against the supposed religious moral code at the time. Certainly it was an offence against the state, as though you said to the state: 'You don't own me. I shall choose this path'. Traditionally in most western cultures, certainly under the old British system, if a person suicided they were buried in unconsecrated ground without benefit of clergy [inaudible]. That is historically the perception of death, I think.

The next area I would like to address is the remote areas of the NT. My reading of the bill as such is that there is a failure of the bill to address the needs outside Alice Springs and Darwin. The reference in one of the clauses to the 2 medical practitioners would rule out a lot of people having access, to be able to give informed consent to 2 medical practitioners. The reality is that we do not have enough practitioners in rural remote areas, as all of you are aware, I am sure. One of the ways I saw of trying to address this shortfall is that if voluntary euthanasia is made lawful under the bill, more people may opt to die at home rather than in hospital. That is certainly the case interstate, where voluntary euthanasia is probably being performed illegally. [Inaudible.]

Section 6(c), I think, needs a slight amendment in relation to that. I would suggest that an authorised person, whoever that is, such as exists interstate in relation to Mental Health Acts and/or Communicable Diseases Acts here in the Territory we have authorised persons under the Communicable Diseases Act where you can give some force to some of the things [inaudible] in relation to infectious diseases perhaps authorised persons within particular systems in communities need to be created, so that they will become the second person. I think it would be an unnecessary burden on an already overburdened health system to expect that 1 doctor could be there and do it and another 1 be flown in just for that.

**Mr POOLE:** I guess it really will depend, if the bill is passed, on the numbers. Marshall Perron is of the opinion that we are only talking of about a dozen or 14 people in the whole of the Northern Territory. Even the majority of those would be in the larger centres, so you probably are talking of about 3 or 4 occasions throughout the Territory outside the major centres.

**Mr ALEXANDER:** Sure, but regardless of what may have been said to the committee prior to my arrival, we are looking at the bill not just for today but for 10, 15, 20 years' time. I predict that it is going to become more easily accessible, and there will be traditional people who will tap into this. I have no doubt. When I first came here, if you talked about things like infant male circumcision being performed in hospitals, that was pretty much unheard of. And yet there are now people choosing to have that done in hospital under general anaesthetic rather than in the traditional setting. .That is one big change. There are sorry, I seem to be digressing.

**Mr POOLE:** No, no, that is a very valid point.

**Mr ALEXANDER:** There are Yolngu women now who are choosing to have some types of surgical intervention that they would not have dreamed of doing prior to this very young generation [inaudible], certainly not among [inaudible]. Procedures for sterilisation, whatever, were a no-no. Women were not permitted to make those sorts of decisions. So I am thinking about what is going to be happening in the generation that is coming along.

**Dr LIM:** Are you saying the numbers will increase, or do you think ...

**Mr ALEXANDER:** I am predicting that the numbers will increase.

**Dr LIM:** Did you say something, too, that perhaps the conditions will extend as well? You did not say that, did you?

**Mr POOLE:** What he is saying is that the cultural changes that have already occurred, you have to expect them to occur in this area as well. While there is a cultural thing against it, that might not be valid in 5 years' time. I think that is what you are saying, is it not?

**Mr ALEXANDER:** Yes, that is right. I have personally been approached for information in relation what is currently effective with our Natural Death Act. I know that there are some people who would be willing to look at voluntary euthanasia as an option, if it is legalised, so that they could put somebody else on the spot to be assisting them, rather than trying to deal with their death through the Natural Death Act.

I think the bill fails to give adequate protection to practitioners who are going to be called upon to do this. I think in Section 9 an extension is required. The documentation by practitioners of assistance in voluntary euthanasia may be used to preclude them from travelling to or gaining entry into some overseas countries. I do not think that is as farfetched as it sounds. I would suggest that documentation pertaining to the performance of VE be removed from the patient's file and secured at a central repository in Darwin. Such files could be accessed by authorised persons if required, but would not easily be accessed by the press or public.

**Mr POOLE:** The way the righttolife debate has extended in the United States, you would certainly want some confidential process with regard to the names of doctors who are actually doing it. Otherwise you will have some loony come along and shoot them or something let alone the payback side of things.

---

**Mr ALEXANDER:** Yes, from both cultures, Aboriginal and nonAboriginal, [inaudible] be coming under threat.

The future of voluntary euthanasia in relation to AIDS ... The number of people desiring euthanasia has increased with the onset of the AIDS pandemic there is no doubt at all about that. And it is certainly occurring in our larger cities, where sympathetic physicians are being called upon to perform voluntary euthanasia at great risk to themselves and others. In the past this was not so. I believe that in the past most people would be looking at euthanasia as a thing for our elderly population. I think we have this mind-set that voluntary euthanasia only applies to people who are 65, 70 or 80. Most people who are suffering from AIDS in Australia are less than 50 years of age. They are the ones most likely, I feel, to offer for voluntary euthanasia compared with the elderly. The elderly may more likely have been raised under the then [inaudible] suicide as a crime/sin. I think for our younger population the same does not hold true.

I want to briefly address the Yolngu cultural aspects. I did not hear any previous speakers. I already had this. Obviously I speak as a nonAboriginal person on this bill, but [inaudible]. My experiential model indicates I may say things to the hearing here that Yolngu elders may not say to Balandas that is, to white people. I think we fall into the trap, when we go into communities, [inaudible]. Once the Yolngu here get to know you and trust you and adopt you in relationship terms, then they have good senses of humour. They can tell you the most incredible stories sometimes, suck you right in. You go away and write a book, like poor old Margaret Mead in Samoa.

That is certainly the case with me. I have an adopted family at Milingimbi. They are also very quick to correct you. If you make a mistake in addressing somebody in relationship terms, you will very quickly get a slap. [Inaudible] tell you 3 times and you should know that if you call a person [*language*] that is really your grandfather on that side and you have made a mistake with the language in relationship terms, so you get a good smack. They only do that, obviously, when they feel very comfortable about doing it to you. It is not meant to be insulting or intimidating.

I have no doubt that if it becomes an option, some people will take up the option, sometime, somewhere. Non-voluntary euthanasia was certainly practised. I have twin boys. When my twin boys arrived, it was greeted with great joy out at Milingimbi. What we do know, from what we were told and what we observed, is that second twins were usually killed. In fact, there was only one surviving set of twins in the whole of East Arnhem in their 20s now until fairly recently, when we have seen more. So that was certainly practised, Yolngu nonvoluntary euthanasia.

**Mr POOLE:** What was the reason? Just for the sorcery reason?

**Mr ALEXANDER:** Partly, yes. But that is not unique to Yolngu culture. It was certainly carried out by some ancient peoples, especially in powerful families where it would give rise to disputes over heritage rights. The Romans certainly practised it and the Greeks

---

did, and I think the Egyptians did it in their royal [inaudible]. If they had twins they would kill the secondborn. That was more of a political/social thing, to stop unrest arising. Some of the royal houses in the African tribes [inaudible] also practised the same thing: the secondborn twin was killed. I think in some other cultures it seemed that there was a galka, a bad spirit, and some sorcerer has cursed it, and it may be that the second baby is not really a person. So it is quite legal to do that. I hope I do not offend anybody out there who reads or hears this.

As far as I am aware, from my readings and my experience and my [inaudible], certainly not now. In fact, because some white people have come here and had twins, there has been some crosscultural meeting. My wife has been called in to help some people to have twins, because to them in some cases it has been quite distressful. So she will take up photos of the boys. She got me to take our boys up to the hospital 1 day to visit a lady who just had twins, as a way of saying: 'Look, there are 2 of them, but they are healthy'. Obviously we were not putting our own values onto these people, we were just [inaudible] make it easy.

Suicide is certainly rare in Arnhem Land. There had only ever been 2 recorded cases up until 1990. Then there was a spate of some recent ones. I might add that the recent ones were not related in any way to anything [inaudible]. But certainly the Natural Death Act, as we would read it, has been applied in traditional culture, where withdrawal of treatment and support has occurred. I refer you to Elizabeth Reid's book on sorcerers and human spirits, published by Queensland University Press. She was a social anthropologist who lived at Yirrkala for many years. She described the system that occurred for that to happen. And it was certainly with the agreement of the community in which that person lived.

**Mr POOLE:** You have to stop feeding people.

**Mr ALEXANDER:** Yes**.** The person would be left lying, the family would sit close by within calling distance. There would be a cup of water put out that this person could observe and call for if they chose to make that decision. The rest of the community would sit farther back and observe, and wait for the end. We do not traditionally do that in our culture, we run round [inaudible] tubes and feeding them up [inaudible]. I guess we are a little more enlightened now, and we do try to make it a little easier. [Inaudible] used to fight tooth and nail. [Inaudible] I think orders not to resuscitate people have only come in in our generation. I think that is just about all.

**Mr POOLE**: Very interesting.

**Dr LIM:** Are there lots of AIDS sufferers up this way?

**Mr ALEXANDER:** No, we do not have any HIVdiagnosed at all in Arnhem Land. But we have and this is public knowledge fairly high rates of other sexually transmitted diseases. So it is reasonable to say that we are going to get it. It is really a matter of when, not if.

**Dr LIM:** Do you think Yolngu people, if they did get AIDS, would request euthanasia? Or do you think they would still go through a traditional ...

---

**Mr ALEXANDER:** I could not possibly answer that on behalf of the Yolngu. I think everybody in that situation would have [inaudible] themselves. Particularly some younger people, it might be easier to ask. It would very much depend, I think, on their contacts with people with AIDS outside of their own culture in other places. There are certainly some gay activist Aboriginals in Sydney whom I have met at national conferences and things, and they would certainly see it an option for themselves. I do not know how they would go if they went back to their communities [inaudible].

**Dr LIM**: It is my personal perception that there is a culture within the mainstream AIDS sufferers that suicide is the way of final selfdelivery. I believe it is a culture, rather than just a deliberate choice or a learned choice or a wellthoughtout choice. It is a culture within the AIDS subgroup. It is the cultural expectation: 'This is the way I want to die. I am an AIDS sufferer, this is the way I will die,' and they choose euthanasia. It is a cultural thing, within that subculture, rather than saying, 'Hey, I'm an AIDS sufferer, but I am going to die just like everybody else'. I have not come across one AIDS sufferer who says: 'I want to die like everybody else'. Instead they say: 'I want to die like every other AIDS sufferer, by euthanasia only'.

**Mr ALEXANDER:** This is something I have never heard yet.

**Dr LIM**: Not a single HIV/AIDS person will say anything else but, 'I will die by voluntary means, by selfdelivery'. I know the subculture of that.

**Mr STIRLING**: There is enormous support within the AIDS support groups and awareness groups here for the legalisation of euthanasia.

**Mr ALEXANDER**: Yes, I believe the Northern Territory AIDS Council and the AIDS Council of Central Australia have certainly taken a strong stance on that. I think that probably there are cultural groups interstate [inaudible] would be watching very closely to see what will occur here, and they will use that as a lever interstate, in government circles. There have been lots of people with AIDS in Australia who certainly [inaudible].

**Dr LIM:** It is another terminology, a new age language, that they have actually brought out themselves. They call it selfdelivery. I guess that is their terminology nobody else uses that term but themselves. That is what adds to my belief that it is a subculture's cultural expectation.

**Mr ALEXANDER**: Rather than the disease ...

**Dr LIM**: No, rather than their being part of the main group [inaudible] Australia.

**Mr ALEXANDER**: I guess my concern has been, from a professional point of view, that some of the best people that I have ever looked at have certainly assisted people I am not talking about AIDSrelated cases now, I am talking just mainstream people, if that is the correct terminology these days and I hate to think that they would ever be put in a position where they would be prosecuted under our laws. Certainly in some of the units at the big hospitals [inaudible].

**Mr STIRLING**: With your experience with Aboriginal people in local communities, do you not think that fear and misunderstanding and anxiety are ...

**Mr ALEXANDER**: Massive! Massive fear and misunderstanding.

**Mr STIRLING**: To the point of maybe affecting delivery of health services?

**Mr ALEXANDER**: I do not know that this is being distributed and read. All that they have heard is what is on the media, and what you hear in the media is what you want to hear. What some people hear is very narrowly focussed, and it is: 'My goodness! If I go into hospital they are going to kill me! If I am incurable they will make the decision to do it for me, whether I want to or not'. That is no different from what our grandparents thought, [inaudible]. If you were going to hospital, you were going there to die. You did not go into the hospital to get killed in those days, you went in because you were terminal. If you were only a little bit crook, you stayed at home and the family looked after you.

Remember, when we are talking about us Balanda, us white people, sitting here on the outside looking in, we are being asked to make assessments on something that is very culturally orientated. Remember that it is only within living memory that most Yolngu people would come to hospital here. Culturally, it was a massive offence to take somebody else's faeces or blood or urine voluntarily and start subjecting them to tests. If you are talking about sorcerers, that is how sorcerers dealt with people here, by stealing some of their sacred body bits and then subjecting them to sorcery, casting spells from it. So here we are, these nice benign people in the health care system, saying, 'Just wee in this bottle, I want to take some of your urine away', or, 'Poo in this pan, I need to test it', oh, no! You see, it has taken quite a long time to convince people that we were not meaning any harm by this, that it was for everybody's benefit to find out what was wrong and try to help.

Traditional people did not want to come to hospital and have babies, but that was right across the spectrum in Australia not just Arnhem Land. It has only been in probably the last 30 years in far western New South Wales, people living semitraditionally out there felt happy about going to hospital to have babies. It took a lot of effort to convince them that it was the best thing to do.

**Mr RIOLI:** So you are saying they are changing their ways now and they are accepting that what is being done is ...

**Mr ALEXANDER:** More so in this generation.

**Mr RIOLI:** Would this bill again change their perception?

**MR ALEXANDER:** I think there has to be a lot more information exchanged out there before people are comfortable with it. You are certainly not going to educate everybody, because even in a white society we are going to have people who have this mind-set that this means murder, regardless of how well it is explained to them. There needs to be a lot more information.

Unfortunately for some groups, who have probably got the best communications into Aboriginal communities here, they also are working from a bias. It is very difficult to stand back and be objective about this whole thing. We are all going to be fairly subjective in one way or another. If you are asking who has the best lines of communication into the communities here to disseminate and discuss the information at a particular level, they may be people who are totally opposed to it. So you are going to get a sort of Hutchinson effect, observer bias affecting the outcome, so they still would not be giving informed consent to the bill. Not that they are going to be asked to vote on it.

**DR LIM:** The only way to do that is to have a robot delivering the message. It is well nigh impossible to do that, obviously. But from a professional point of view, will it alter doctor/patient or professional/patient relationships?

**MR ALEXANDER:** I think it is bound to in some cases, where people would not want to go to a doctor who they thought was performing. But then again, you would find that some women who are totally opposed to termination of pregnancy would not go to a GP who may offer termination of pregnancy as an option.

**MR POOLE:** Or would it?

**MR ALEXANDER:** Yes, it would in some cases, I think, for the better. If I were of the opinion that I should be given the privilege of choosing to die or not die at a time to suit me, because I was terminally ill, I may be biased against doctors who would not perform it. I would certainly keep it to myself, but I would not go to them for a lot of other treatments. Even though they might remove ingrown toenails better, I might ...

**DR LIM:** This might be a leading question. Even if he was your doctor for the last 10 to 15 years, suddenly you hear that he is not one who supports euthanasia, what do you do in that instance?

**MR ALEXANDER:** I would have to continue to go to him after that length of time, but if I was getting terminally ill I would not. I would certainly give him the option to say yea or nay. I would then expect him to refer me to somebody who was prepared to. If he did not, I would see that as being an act ...

**DR LIM:** But as the law sees it, he does not have to refer you.

**MR ALEXANDER:** Ethically, I see that. But do you see, there is a strong argument that if somebody goes to a practitioner and says, 'I've been using intravenous drugs and I want an HIV test', and the person says, 'No, I'm totally opposed to drugs and I'm not going to offer you that service', then in good faith they could say, 'But why don't you go and see soandso?' It is the same with termination. If a termination of pregnancy situation arises and the practitioner of any discipline within health care says, 'No, I can't do this', they cannot abandon their patient. To me that is unethical. They must be able to refer them to somebody else who can. Otherwise they are merely putting their own values onto the patient who has come to them for help. Sorry.

9

---

D**R LIM:** No, that is fine. I just wanted to hear what you had to say, that is all.

**MR POOLE:** All right, any problems? Thank you very much very interesting.

select COMMITTEE **ON EUTHANASIA**

**MILINGIMBI COMMUNITY INC.**

**PUBLIC HEARINGS**

Friday 7 April 1995 Opened: 10.35 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives:

Mr Alfred Djapundawuy

Mr Jackie Barakal

Mr Henry Djerringal

Mr Mathew

Mr Joseph Watjun

Ms Elizabeth Gayngulpa

Mr Charlie Maydjarri

Mr Joe Nulundurruwuy (Mawundjil)

Ms Kaye Thurlow (School Principal)

Mr James Gaykamanu

**Note:** This is an edited transcript.

**Issued: Tuesday 18 April 1995**

1

---

**Mr POOLE:** Thank you for your welcome here. We have been asked to come and talk to people all around the Northern Territory. We have been talking to people in Alice Springs, Hermannsburg, Tennant Creek and Katherine. Yesterday we talked to people in Nhulunbuy and out at Yirrkala. At Yirrkala there were also people from Lanhupuy Associations, the homelands. And now we are talking to you about this bill.

This bill is for people who are very sick. This bill is for people when they are dying, when they are very sick and they have a lot of pain, a lot of suffering. They can ask the doctor, if they want to, to help them finish their suffering. They can have an injection and go to sleep forever.

Some Aboriginal people told us that that is not the Aboriginal way. They think it is better for the people to be at home with their people. They say the problem for Aboriginal culture is that when people die, they know and the land knows that they are dying and they do not want a doctor to interfere. They do not want the doctor to do anything.

We have come here not to tell you, we have come here to listen to what you have to say.

This law is a different law. Usually a law in the Northern Territory applies to everybody. This law would only apply to people who say: 'Please help me'. People must ask for this law to apply to them. The doctor has to say: 'Yes, this person is very sick, and I cannot do anything more with medicine. They are going to die'. Then the doctor has to ask another doctor to talk to the person, and agree with the first doctor that the person is sick and is dying and that they want it all finished.

This bill is not a CLP bill or an ALP bill. It is a bill proposed by a member, Marshall Perron. We have to talk to everybody in the Territory and go back to the parliament, to the Legislative Assembly, and tell the Legislative Assembly what everybody thinks about it. Some people will say it is a good bill, other people will say it is a bad bill. So far the Aboriginal people we have spoken to say it is not a bill for them. But we want to talk to you about it. We want to listen to what you have to say. If you want to speak in language, that is okay. We will get translations and make sure everybody in the parliament knows what the people of Milingimbi think about it. We will tell them, and we will also have all that you say written down and given to all the members in the Assembly.

Anybody who wants to talk or ask questions, please come up. And thank you for having us here in your community, and for helping us to set up this meeting.

**Mr BARAKAL:** We are Yolngu people of Australia. Say, if 1 Yolngu in Central Australia says, 'That is not our bill', that is enough for Yolngu people of Australia. Thank you.

**Mr DJERRINGAL:** [*Language*].

**Mr Matthew ... [surname not recorded]:** [*Language*].

2

---

**Mr WATJUN:** [*Language*]. Speaking in European language, European people that support my people [*language*] what is good for the future. These groups, thinking like Marshall Perron or somebody else, are planning the sorts of things that are good for the Yolngu people and Balanda Europeans in Australia. But we have to put to these people [*language*] what is our feeling, because we are people with lives. We know that our lives are precious to the Creator, in special ways. [*Language: question to audience.*] Do you like these sorts of things done for you, by a doctor, like this doctor? Where is Dr ... Only one, eh? [*Language.*] We have to put to them what our feeling is. I would appreciate it if my own people who have gone through qualifications would help us. I am an old man and do not have the qualifications. Please support me, and speak for me and my people. I will appreciate it, really, of these people, too, if they have to take it upstairs and put it through this parliament.

It is all right in Australia, because life is very precious. You have not heard anybody who has been nearly dead, but sometimes a doctor heard them, heard what they said. And they are nearly to death, eh? That person is feeling their life for the last time. I think this man will be agreeing, because in those last days some of our professional doctors, in that room to listen to that patient when they are nearly dead, but sometimes God brings that life back to that person, whether white or black. So we have to leave those with the local people, because life is precious, very precious, in God's sight. God is feeling the life not people here. People here are feeling only the body here, not the life. So let us let God deal with the life.

That will be my [inaudible] brothers and sisters in Australia, whether black or white, red or yellow. I will come back later on, I have more to speak on this matter. If I talk a little bit long, please stop me. [*Language*.] This is a message for both our government in the Northern Territory and our government in Canberra, the Commonwealth, who have to provide us good medicine, good money to spend. They have been doing these sorts of things. I appreciate it and I am thankful to these people. But this is very bad, interfering with the life of the people. Take this message to that minister there and for the Commonwealth. We do not want these sorts of things to happen. When they cannot do anything further for a patient, please send that patient back to home to the people, so we have to look after them ourselves. [*Language*] my cousin is there in Parliament House, Wesley Lanhupuy. I am speaking on behalf of my people, both white and black, yellow and red, because our life is precious. [*Language*.] Thank you.

**Mr POOLE:** Dr Lim has asked me to say to you that in the Northern Territory and in the rest of Australia, lots of doctors have said that this bill is no good. Other doctors have said it is a good bill. Some nurses have said it is a good bill. Other nurses have said it is not a good bill. Maybe some of the women here want to come and talk. We want to hear what the people here think, so that we can take the message back and tell other people in the parliament what you want. If you do not want this bill, you must come and talk about it. If you want this bill, you should come and talk about it. In the parliament in the Northern Territory, lots of people already have said they are not going to vote for the bill. Other people have said they are going to vote for the bill.

Marshall Perron has said: 'If you don't like the bill, you don't have to ask the doctor to help you nothing changes'. Other people say that is not good enough, this bill should not be allowed anyway. But it is up to you, the people of the Northern Territory and the people here. So please come up and talk to us so that we can take your message back to the parliament. You have your local member here, Wes Lanhupuy. You should be talking to Wes and telling him what message you want him to give to the parliament back in Darwin. We will be talking about it in May not very far away, one month. It is important that you come and tell us what you want. Thank you.

**Ms GAYNGULPA:** I am speaking on behalf of my community of Milingimbi. This statement is for my mother. She died [inaudible] at the clinic here. I would like to express my feelings about this thing called euthanasia. We do know that there are certain illnesses that are incurable, and we do understand that some of the illnesses have long suffering periods. We, as relatives, do not want or like the idea of euthanasia practised on our terminally ill relatives. While [inaudible] it is necessary to say a word about suffering that comes from the sickness. I think [inaudible] difficult, and despairing happens with this. However, of course there are those among my people who believe in [inaudible] healing. I certainly do not think that the idea of practising euthanasia on Yolngu people is acceptable. We were never meant to be dressed in clothes, and we were never meant to be introduced to [inaudible] laws as [inaudible], and taking tablets when we are sick, and working for money and living in a house that we have to pay to keep the electricity going. We were never meant to be living like that, but we have to do this thing because we are living in a western world. We were and are nomads. We were hunters, food gatherers, ceremonial and cultural people.

We just want to, and will, give comfort and tender, loving care to our terminally ill relatives. Our terminally ill relatives know that they are dying and they always want songs to be sung their traditional songs in the last days of their lives, and the sound of the didgeridoo and the clapsticks. Finally, I would like to let you know that most Yolngu people are Godfearing people and were introduced to Christianity by the first missionary who came to Milingimbi. We have heard and read the Bible, and it tells us that Jesus heals. All you have to do is trust and believe in him. Thank you.

**Mr MAYDJARRI:** [*Language.*] I know it, that is what should be. It is part of our lives. A woman has said this, too. It is almost our code of life. That is what should be. The things we do not know, we do not like. Doctor, if a person is suffering with sickness, do not ever come round with a needle, killing people. That is not good enough. Suppose myself, if I suffer for so long and doctors and nurses are sick and tired of me, looking after, feeding me, giving [inaudible]. Then after all they might think: 'We kill this person, we are sick and tired of him'. That is not good enough because the doctor is stealing not money he is stealing the lives of people. That is what could be. When doctors or nurses come around with pills or a needle, killing people, that is not good enough. Murdering somebody else, that is not good enough. What God wanted, for a person who suffers so long, is just care and love until he is [inaudible] to die himself but not use pills or needles to kill somebody else. If that happens, everybody in the community who are not interested go down the plughole.

---

If somebody is sick here or ill, it is really hard for a person to go to the hospital. Even whole families will not attend the hospital because they are scared of the doctors or nurses with pills or needles. So leave it out. Leave it to the community as it is now. Do not change everything. Just leave it to Yolngu people as natural, as it is now. Thank you.

**Mr DJERRINGAL:** [*Language.*] ... working in the hospital, and they said it is [inaudible], it is recommended. That is their story on the day. There is somebody else not talking. Every bits and pieces of [*language*]. If we were working together, living together, one nation, [*language*]. Tell me, are those other people [inaudible] some of the women agree, [*language*]. If we were working together, we are not going to do anything about ourselves. This is a matter for black and white folks, no matter what colour. If we want to live together, one people, one nation, [inaudible]. We are Yolngu people. When our old men get sick we want to respect them, like we want respect nowadays from somebody else with respect for us. [*Language*] all our lives. [*Language.*] It is against law, the killing, against Yolngu law. [*Language.*] Somebody else is going to get killed. [*Language.*] We are not going to have our old people or any sick person in our [inaudible], you are going to get killed. [*Language.*] Healing! Healing! [*Language.*] Thank you.

**Unidentified speaker:** Good morning, everybody. Some of us do not know and some, we do know about this meeting. We are talking about human life. A human life is like $1 million or $10 million. When you own something it is yours. Blood is very important in the life of people and the life of God. People have been heard for many years saying, 'treaty'. That treaty is only in the air it is not reality. We want reality from government, whoever. I want to talk about maybe 2 things. First one is justice. We want to see justice in government, in hospital, wherever, there must be justice for humankind. Treaty is not enough. Treaty has been [inaudible] for 50 000 or 60 000 years ago. This is the new world. People can see what is wrong and what is right, what is bad and what is good. We want to see justice to happen to black people from the whites. There is no recognition among Aboriginal people in Australia. There must be recognition, because we are the first people. Balanda, the white people, were the second people. Henry was talking about unity, but we have 2 kinds of culture, one white culture and one Aboriginal culture, and these 2 cultures must be recognised. We are different people living in this world. There is your culture as well as ours. There must be recognition also. And there must be justice in hospital from the government towards the Aboriginal people. I want to also say that if the doctor cannot do anything for a person, please send the person back to home. He or she can die at home. It is not meat in the abattoir or fridge. It is a human. Send it back, because we can look after them. Do not do anything, just say you cannot do anything. It is better to send home and do not keep it there. Thank you very much.

**Mr WATJUN:** [*Language.*] What I would like to know is, how did he know that he had to do these sorts of things for us, both Balanda and Yolngu? Because some Balanda, a doctor here, some doctors, support [inaudible] people around Australia. [*Language.*] Please, you mob have to go back and get them to do this sort of thing there for us. Explain to that minister, or any politician in Australia, about the things that we do not want. I support 100% the minister here, that he speaks on behalf of our community here. I would like Balanda based here elsewhere too to come and speak on behalf of your community. [*Language.*] So we

---

have to first go through our minister to recognise that he requires that this mob here and those mob there, lot of talking going on there for us, but they do not know local people, local areas. Thank you.

**Ms THURLOW:** I am the principal at the school here. I have been living in Arnhem Land over the last 25 years, though not here all the time. I have an understanding of Yolngu and what they have been saying this morning, too. I would like to share a couple of things myself as well. For Yolngu, one of the things that we probably need to understand more is that this is not a law just for Balanda. It is for everyone. Balanda culture has lots of problems, wondering what to do about our relations when they get very old and when they are dying and we know they are dying, just like you know your relations are dying and we see them suffering, in lots of pain, and we are crying for them because they are in lots of pain. We are thinking, how can we make it easier for them, for these last days or these last weeks, when they are in lots and lots of pain? I think that is where this law is coming from first, because Balanda, especially Marshall Perron, he has been seeing people in lots of pain before they are dying and he is asking: 'How can we make this easier?' That is why, I think, he is thinking: 'Can we maybe help those people we know are going to die? Can we make it quicker for them to die?'

I was really very sad when my father passed away at Christmastime, but I was feeling happy because he was only suffering for a short period of time. First he was feeling okay and then he got sick really suddenly, and he was only suffering for a short period of time and I was feeling happy. But if he was suffering for longer, months, and yet still knowing there was nothing the doctors could do to help him, maybe I would be thinking like some of these people who want to make this law. So that maybe my father says: 'I know I am dying. Can you make it quicker for me to die?' The Balanda, that is what they are thinking. But when I sit around here with Yolngu who are sick like that, then I see a different thing altogether. I see Yolngu who say: 'I am the old person, I am really sick, I know I am dying ,but I want to go home to my family, sit with my relations and listen to my relations sing my songs, bringing my culture in to me, helping me on that journey from being sick and dying to where I am going to after I die'. Whether we are Christian or not, we still want to listen to those stories. I think Yolngu have got a lot to teach the Balanda about how to help old people to die. What we are trying to say here is that Yolngu want to be able to have a chance to be gentle and caring for terminally ill people, but we do not want them to die any more quickly than they would naturally. We want them to go in their time, not to be helped by the doctors to go more quickly.

The other thing I am really concerned about is this. Even in just talking about this law, it needs to be made very clear to us, so that Yolngu are not going to be scared to go to the health centre, scared to go to the doctors, especially if we know they are really sick. I think it has already been said, and it will be even more worrying, especially in these next few months or years, that maybe old people will not go to a doctor any more because we have been talking about how the doctors might help them pass away. That is a real worry for me, just raising these questions.

So we need to be explaining that, first if this law does not get passed, but also more so if it does get passed, exactly what the law would mean that it is not someone else saying that a person be helped to die by the doctors. But exactly what does it mean? At the moment, I think, we are just talking about ideas, but even if the law is defeated when it is brought up in the parliament, we now have a lot of teaching to do to convince and assure people who really have never been very trusting in lots of ways, or very nervous of the medical profession. Now we have an extra problem of not trusting those Balanda doctors, just because we have raised this question. My request is that whatever we do, we will need to bring back some more teaching, whatever the law becomes, whether it is passed or not passed. People who do not understand will need to be assured of what exactly this means. I think at the moment we do not really fully comprehend what it is all about. Thank you.

**Mr POOLE:** Today I think we hear your message, that you want us to go back and talk to the parliament about. That is what I said when we started talking. We have come not to tell you, we have come to listen. We have come to take your message back to the parliament and your message is, I think, very strong. The message is that you do not want this bill. You want your people to come home when they are sick, to come back to their land. You do not want the doctors to do anything to them, you want to bring them back to their home and to their family. We will take that message back to the people in the parliament when we are talking to them.

What the lady schoolteacher was saying I agree with. We must make sure that everybody understands whether or not this law is passed will have no bearing it has no effect on anybody unless the person says: 'Please help me, because I want to die'. Nobody is going to do anything to anybody in the hospitals at all without their asking, so there is no reason for old people or sick people to be scared or to be worried about going to the hospital.

We will take your message back. Your message is that you do not want anybody to interfere with your culture. You want to bring your people home, back to their mother earth. I think we all understand that. I thank you all for coming to this meeting today. We have to go on to talk to the people over on the islands this afternoon. I assure you that Maurice, Wes, all of us, will make sure that the parliament hears your message very loud and very clear. Thank you very much.

**Mr GAYKANANU:** [*Language.]* I want to thank you very much for coming, bringing this message, because we did not know what euthanasia meant to Aboriginal people. We will appreciate it if you take that message to the parliament and inform them what our needs are. Thank you.

select COMMITTEE **ON EUTHANASIA**

## NGUIU COMMUNITY GOVERNMENT COUNCIL

## PUBLIC HEARINGS

Friday 7 April 1995 Opened: 13.55 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives:

Mr Barry Purantatameri, President

Mr Hyacinth Tungatalum

Mr Owen Tipiloura

Mr Eugenio Purantatameri

Ms Vicky Gordon, Nurse

Ms Judith Puruntatameri

Ms Esther Babui

Ms Teresita Puruntatameri

Dr Justine Mayer

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr B PURANTATAMERI:** Welcome to committee members.

**Mr POOLE:** Thank you. We have been travelling around the Northern Territory talking to people about this Euthanasia Bill. We are not trying to make you make a decision about it, we just want to take the messages back that you want to tell us, so all other parliamentarians in the Legislative Assembly know what the people think. We are recording everything. They type it up, copy it and they will give it to all the 25 members of the Assembly.

I will tell you a little bit about the bill. Marshall Perron introduced the bill, but it is not a CLP bill, it is not an ALP bill. It is a private member's bill, all right? It is just an idea that he has, that sometimes the people who are very sick and are dying, it is a bill to help finish their suffering. I guess you all know, sometimes people get disease or sickness, like cancer, and the last part can be very, very painful vomiting and lots of stomach cramps and all kinds of things like that. If a person wants to, they can say to the doctor: 'Please help me. Put me to sleep and help me die. Make it more quickly'.

Some Balanda people think that is a good idea, because they have seen maybe members of their family die very painfully. Other Balanda people think it is not a good idea, that we should not interfere, that the process of dying should be left natural and not be interfered with, not quickened up by a doctor.

Some of the Aboriginal people we have spoken to, almost all of them, have said: 'No, we do not like that idea. Our way, our culture, is that when somebody knows that they are going to die, the land knows they are going to die, too. They must come home and be on their land with their family'. They do not want the doctors to do anything.

For Balandas, it is very much a personal choice. The doctor cannot say: 'I am going to give you an injection'. If you are sick you must ask for it. Nobody else can do it for you. You have to tell them that is what you want.

I understand that in the Aboriginal way, that would be a family thing, not one person to say something like that. But we would like to hear what you have to say about it, what you think.

**Mr TUNGATALUM:** Firstly, I think the law should not be made for this. The law should not force anyone to make them do those things. The law should not be made for this purpose.

**Mr POOLE:** But it does not force anybody.

**Mr TUNGATALUM:** But a law should not be able ...

**Mr POOLE:** No, okay. I hear that. But you must understand that nobody can say: 'You are going to die. I am going to give you an injection'. It must be the patient saying: 'I want that because I have so much pain. I want you to help me'.

---

**Mr TUNGATALUM**: It is up to ...

**Mr POOLE:** Up to the person that is sick himself, yes.

**Mr TUNGATALUM:** I found one old fellow, long time ago, he was very, very sick. One day he said: 'The Lord take me away. He give me great pain [inaudible] if that's the way he wants it'. But a lot of people, a lot of Aboriginal people do not want that, they want what you said, for the same idea, [inaudible]. But these old people, on their land, [inaudible]. One day he is suffering, he still [inaudible] comfort from that. This is probably some way different in the European society.

**Mr POOLE:** Lots of Balanda like it that way, too. [Inaudible] should be with their family and together.

**Mr TUNGATALUM:** But Yolngu people when they are very sick we all stick together. I do not believe this bill should be made [inaudible] euthanasia.

**Mr POOLE:** I should say to you that even in the parliament some people will probably think it is a good law, some people will probably think it is a bad law. You should understand that when Marshall Perron spoke about it in the House, he spoke about it as a law to help people, not to hurt them to fix their pain, fix their suffering, finish it quickly.

**Mr TUNGATALUM:** So 1 or 2 days he might be feeling very, very sick. Might be that day he wants to say: 'Get rid of my pain'. But if maybe a few days after, he might come good then he would be dead by then!

**Mr B PURANTATAMERI:** You find some people are diagnosed [inaudible] and possibly living for 10 years. If we believe as we were brought up as Catholics [inaudible] euthanasia, against it. The man upstairs, it is his job, when he is ready, to take that person [inaudible].

**Mr POOLE:** And that is very important, too.

**Mr B PURANTATAMERI:** It is up to the individual people.

**Mr POOLE:** And even if the law did go through, we must make it very clear that it would still be an individual thing, so that people should not be scared about going to hospitals or talking to doctors or anything like that. There are many doctors and nurses that do not [inaudible], but there are some doctors and some nurses that say it will be good to help [inaudible]. But even the white community, the Balanda, are very divided. Some say yes, some say no.

**Mr TUNGATALUM:** Some doctors and some nurses and sisters, after looking after a patient for that many years, they get sick of it. Might turn around and get rid of them.

**Mr POOLE:** No, I do not think you would see people like that.

---

**Mr TUNGATALUM:** I have heard it on the TV long time ago.

**Mr POOLE:** Yes, I think people say things like that, but really all the doctors we have spoken to, the ones that think it is a good idea, they say that on the basis that they are sick of seeing people dying really badly, really painfully, they would only do that to help the person, not to ... Really, they look at it as putting them to sleep forever, rather than being badly treated. Same result, but you know ... I am quite sure that Marshall Perron is not looking for a way to save money or to stop people caring for people. He sees it as a way to let people help somebody that they love to stop their pain and suffering, that is all.

It is the people, you have got to decide. So far the message from Aboriginal people to all of us has been that they do not want it, because it changes too much of the culture.

**Mr TUNGATALUM:** I have not seen a draft of that bill.

**Mr POOLE:** We have it [inaudible]. We have copies.

**Mr B PURANTATAMERI:** Will this go out to referendum?

**Mr POOLE:** No, it will be decided in the parliament among the members.

They do it in Holland, and there is one state in Oregon in the United States where they passed the law that said they can do it, but they have stopped them from doing it because it has been challenged in their Supreme Court.

One of the other arguments among the Balanda people is that maybe in time it will change from the patient saying, 'Please help me', to the doctor saying, 'We have to do that because it is easier for you'. But that is not what this bill says. This bill is very much for the individual only.

**Mr TUNGATALUM:** And family must be involved.

**Mr POOLE:** Yes, well that is the difference, you see. In Balanda it is the individual choice. In my family I would decide. I would talk to my family, but I would decide. Maybe it is not the way of Aboriginal people. Among Aboriginal people the family would decide it. But I think it makes it harder, makes it more complicated for them.

**Mr PURANTATAMERI:** If that bill passes in parliament, that will effect the whole of Australia?

**Mr POOLE:** No, it would only effect the people of the Northern Territory. But there are other states looking at the same bill: the ACT, Tasmania, South Australia. There is now some talk in Victoria as well. The only ones that have indicated they are going to discuss it so far are the ACT, Tasmania and South Australia.

---

**Mr TUNGATALUM:** Maybe this bill can go right through because of AIDS and whatever is [inaudible].

**Mr POOLE:** Yes, I am sure that is one of the reasons. There was already some talk among Balanda doctors that sometimes they do that to people anyway. There has been no talk like that in the Northern Territory, but in Victoria a doctor said sometimes they do that. But they do not do that to kill people, they do it to help people. When you die of AIDS, apparently it can be a very bad death, very painful.

If anybody wants to talk in language, that is okay, because we get it translated.

**Mr TUNGATALUM:** If we translate it we will be here all night.

**General conversation in language.**

**Mr B PURANTATAMERI:** What would happen, Eric, if I, for example, have AIDS and I go along to the doctors do you have to face about 5 or 6 doctors, and the lawyers?

**Mr POOLE:** No.

**Mr B PURANTATAMERI:** Have to be lawyers there, no?

**Mr POOLE:** No, no. It is quite a simple system.

**Mr B PURANTATAMERI:** It is like you want to take my life away.

**Mr POOLE:** No, the way it is in the bill, it is quite a simple system. But when you get AIDS you go through various stages, and when you start getting to the bad stage, under the terms of the bill the doctor must think you are going to be dead within 12 months, not 5 years. It has to be at a bad stage, really. Then if you say, 'Doctor, I do not want to go through this any more, too much pain and suffering. I want you to help me finish it', he has to get another doctor to come and talk to you to make sure that is what you want not what the doctor wants and he has to agree that your illness is so bad that you are going to die within 12 months.

**Mr B PURANTATAMERI:** So how many doctors?

**Mr POOLE:** 2 doctors before it can be done.

**Mr B PURANTATAMERI:** Do you have any witnesses, legal witnesses?

**Mr POOLE:** No. Some people think maybe that is not such a good thing. Maybe you should have a legal witness or something. You have to sign papers and ...

**Mr B PURANTATAMERI:** What about the family? Do they have to sign too?

5

---

**Mr POOLE:** No, it is an individual choice. But the 2 doctors have to agree that you are going to be dead within 12 months, and that it is the right thing to be done at that time. You can have 5 doctors involved if you want, but it must be a minimum of 2. One of the things the doctors have to say is that you are all right in the head, that you are not incompetent of making that decision, that you are not crazy or whatever. If you are unconscious or something, they cannot do it.

They say that you will probably involve maybe 14, 20 people in the whole of the Territory every year no more than that, a very low number of people.

**General argument in language.**

**Mr POOLE:** Do you want me to say something?

**Mr B PURANTATAMERI:** Yes, explain to the other people.

**Mr POOLE:** We just started talking to the council while we were waiting for people to come. We can start again.

**General argument in language.**

**Mr B PURANTATAMERI:** [Language] four people here sitting, that is Eric Poole, Syd Stirling, Richard Lim, Pat [inaudible], and everybody knows Maurice Rioli.

**Mr POOLE:** Thanks for finding the time to come to talk to us today. What we are doing, we have been asked by the parliament and it is a mixture of parliamentarians, it is not all CLP or ALP, it is a mixture of both sides of parliament to come and talk to the people around the Territory. We started off in Alice Springs, we went over to Hermannsburg, we came up the track, we spoke to the people in Tennant Creek, we spoke to the people in Katherine, then we went on to Nhulunbuy, we went out to Yirrkala, and this morning we were in Milingimbi. Today [inaudible] and then next week we start talking to people again in Darwin. We will probably go out to other communities from Darwin as well.

What the parliament has asked us to do is to talk to you about the Euthanasia Bill. It is not my job to try to persuade you whether it is a good bill or a bad bill. We just want to get a strong message from you of what you think, so we can go back and tell all the other people in parliament what the people think. In the Balanda people this is a very big argument. Some people say it is a good idea, some people say it is a bad idea. Even doctors and nurses, some doctors think it is a good idea, some doctors say it is a bad idea. Lots of nurses say it is a bad idea, some nurses say it is a good idea.

I think you should clearly understand that Marshall Perron, who introduced this bill not as the Chief Minister, just as a member of the Legislative Assembly introduced it because he thinks it will help people who are dying very badly, very uncomfortably. It will hasten the process. Now, obviously a lot of people do not agree with that. They think nature should take its course, and it is not a decision that one person should be making.

6

---

From what we have heard from other Aboriginal people, it would be a family decision at any rate, and it does not fit in with Aboriginal culture. That is the message we have had from Aboriginal people so far, that when people are dying they know they are dying, the land knows they are dying, and they should come home to their land, so that they can have their songs, tell the stories and be with their people when they die. That is what other Aboriginal people have been telling us so far. We are taking that message back, and we would like to know what the people here think. I am not trying to convince you that it is a good idea or a bad idea. I just want to hear what you [inaudible], so that we can go back and tell the other members of the parliament.

At the end of the day the parliament is going to vote one way or the other. I can tell you now that lots of people in the parliament do not think it is a good bill. Some people in the parliament think it is a good bill, others do not. But they really need to hear your voices, to be able to read your message. If you want to speak in language, you can speak in language, because we get it interpreted. We have these microphones around the room that will pick up what you say and we will have it translated, and every member of the parliament will read what you say here today. We have already had a bit of a talk with your council. They have said they do not want that bill.

You should clearly understand, the way the bill is written on paper that we have here, it is an individual choice. The doctor cannot tell you to have it, you have to ask the doctor. That fits in, I guess, with Balanda culture, but really does not, I think, fit in with Aboriginal culture. In the white society, if it was me I would talk to my family about it, but I would make a decision. It would be me who makes the decision, not the doctor, not anybody else, whereas I think maybe in Aboriginal culture it would be a family decision.

It is up to you what you say. We will take the message back to the parliament. So if you want to talk, please just speak close to one of the microphones here and say what you would like to say.

**Mr B PURANTATAMERI:** [Language.]

**Mr POOLE:** One of the ladies over in Milingimbi this morning gave us a very strong message to take back. She spoke to us all and she was very strong in what she said. She did not want the bill.

**Mr B PURANTATAMERI:** [Language.]

**Mr TUNGATALUM:** [Language.]

**Mr E PURANTATAMERI:** We here in the Tiwi Islands, we have a strong faith, for we were brought up by missionaries. We have the Christian faith in us. We obey God's law. He created us. From the beginning, he made Adam and Eve so they can do the work. He can give them punishment if it is not done. Now women and men have been [inaudible]. It is the same thing. In our culture we start doing that, and we are going to carry a heavy load all the

---

time, and you are going to take us down to die quickly. See, we still have that blending together, blending our powers or [inaudible]. So we do not need it here in these Tiwi Islands. We just want to die normally, with our pain. [Inaudible] to live and die with us. That is all I have to say.

**Ms GORDON:** I am a nurse down at the health centre. I am not saying one way or the other what I think about it, but my concern after talking with some people in the community is that people do not fully understand what it means. It needs to be really clear what it means. People have different ideas on it. They think they know what it is, although they do not know what it is, and they are saying it is a good idea or not a good idea from that. As you said before, about it being an individual choice and not the doctor's, you cannot say that enough. None of us at the health centre can make that decision for people.

**Mr POOLE:** I guess I should repeat what I said this morning. Somebody over in the other settlement on the mainland said that maybe people would become scared to go to hospital or the health centre. There is no reason for that, because even if the law was passed, it would still make no difference to anybody unless they have said to the doctor: 'I am dying. I want you to help me finish it quickly'. So if you do not ask the doctor to help you to die, nothing has changed. Right now, of course, we do not know whether the bill is going to be passed in the parliament or not. Maybe more people will say no to the bill than will say yes. I do not know that yet. We will see next month. But you should clearly understand that people should not be scared to go to the doctor or to go to the health clinic because of this bill.

For me, I have a big worry with that, because I think whatever happens with the bill, you are going to have to get lots of people to go out and talk to people, particularly in Arnhem Land and over here, to make sure that everybody understands that nothing will change. It will only change if the bill goes through, and if you ask for it. Do you understand what I mean?

**Mr TUNGATALUM:** If this bill goes through, you must come back [inaudible]. You must come back here.

**Mr POOLE:** What will happen, we will take your message to the parliament, and the parliament will discuss it about 16 May. Then about 23 or 26 May they will vote yes or no.

**Mr TUNGATALUM:** Are we going to see the [inaudible]?

**Mr POOLE:** The result will be whether the bill is passed or is not passed. That is why it is important that your message is a strong message that we can take back for you.

**Mr E. PURANTATAMERI:** [Inaudible] the same?

**Mr POOLE:** It applies to everybody in the Northern Territory. But still, it only applies if you ask for it. Usually when you have a law, like about no drinking or speeding, or driving licenses, that applies to everybody. This law only applies to people that say it is for them. If you do not say it for you, it does not apply.

---

A lot of people do not like that. They say we should not change it anyway. It is being discussed right over Australia in Sydney, Melbourne, everywhere and there is a big movement to stop it, particularly with the church groups, the righttolife groups. They do not want to change the law. They say it is not the right of one person to say that, because it changes our society, and they do not want that society changed. And yes, I think that is what you are saying.

**Dr LIM:** The question before was about what is contained in the report.

**Mr POOLE:** When we go back, we are going to get all of the transcripts from tape recordings even the stuff that is done in language will all be translated and it will be given to everybody in the parliament so that everybody can read it. Then we will stand up, just this small group, we will make a report. Now it is not our job to say it is a good law or a bad law. It is our job to stand up and say: 'Look, the people in Tiwi, they do not like the idea. The people in Yirrkala, they do not like the idea. Some people in Alice Springs say it is a good idea. Other people, Aboriginal people at Hermannsburg, say they do not want it'. We have to tell the parliament what you think.

If we ourselves have problems with the law, we are going to stand up and say that too, because even in the parliament people are divided. Some people want it obviously Marshall Perron wants it other people do not want it. I know Maurice is one of those who do not want it. There are both sides.

It has to be discussed properly. It is a very big decision for the parliament, a very big decision for the Northern Territory and maybe for Australia too. It is done in only one place in the world at the moment, a long way away over in Europe, in Holland. A lot of people say that when they started to do it there it was the individual's choice, but now it is the doctor's choice. And nobody wants that.

**Mr B PURANTATAMERI:** [Inaudible] penalty of $20 000. What is that?

**Mr POOLE:** In the bill there are penalties if people do the wrong thing in the procedures. There is argument about that, too. Some people say you cannot have a penalty of $20 000, because in effect you are talking about somebody's life. It is not sufficient to have $20 000 or $200 000 when you are talking about life.

**Ms GORDON:** We have already had a little bit of trouble at the health centre because of this.

**Mr POOLE:** I am sure you have. It is a problem that has been expressed to us as we have done the rounds of Aboriginal communities. It has introduced an element of distrust, I think, probably compounded by some of the more outrageous claims in the media either for or against the bill.

---

**Mr B PURANTATAMERI:** What we said in the early parts of the council this morning [inaudible]. We were brought up in the Catholic religion and [inaudible] only person to take away life is the person upstairs.

**Mr POOLE:** Maybe you could ask the people here. Everybody who thinks the way you think, just put their hands up.

**Mr B PURANTATAMERI:** [Language.]

**Female voice:** We are all against it!

**Mr B PURANTATAMERI:** Put your hands up, please. If you have got anything against the bill, hold your hands up and say your name.

**Ms BABUI:** [Inaudible] Aboriginal way of culture. I think you are aware of that. I am against pushing [inaudible]. We all have our lives, our Aboriginal way of culture. We all have culture. We do believe in God, we are Godfearing people.

**Mr POOLE:** This man here is the member of parliament from Alice Springs. He is a doctor, Richard Lim. Richard just wants to say something.

**Dr LIM:** I am from Alice Springs, so I am from Central Australia, a long, long way away. I work in Alice Springs as a doctor, and for most of a year I have been in parliament with Mr Poole and Syd and Maurice.

This bill troubles me personally. However, I must try to reassure you that the doctors, the nurses, your health centre are here to help to make you better. There is no reason for anybody to distrust the sisters, the doctors, and think that we will not do our very, very best for you. This bill has caused a lot of uncertainty, caused a lot of people to be scared to go to doctors, to go to nurses and health centres, because you think you will get a needle. That is not going to happen ever, even if this bill goes through. Unless you ask for it yourself, it will not happen. That is what we think.

Some people say this bill, once it is passed, will get worse, that eventually other people might get hurt. We do not know that. But the bill is not passed yet, so you must not distrust yours nurses, your health centre, your doctors who come here, because they are here to help as much as they possibly can. I just want to reassure you of that.

**Mr POOLE:** Well, I think we have had a pretty strong message. Everybody has put their hand up. The 4 parliamentarians here, we will take your message back to Marshall Perron when we talk about the bill and when we make our report. As I said to you before, we have already got a pretty strong message from the other Aboriginal areas where [inaudible]. So the Aboriginal people seem to be pretty united that they do not want this bill.

**Ms J PURUNTATAMERI:** Who is going to make the decision for the one who is very sick, the one who has brain damage?

---

**Mr POOLE:** One of the things about the bill is that it is quite narrow in the way it would work. If you are unconscious or you have damage to the brain, or you are what doctors call incompetent to make a decision, you cannot ask. And if you cannot ask, it cannot be done. It can only be done, if the bill is passed, if the person requests it. If they cannot talk, if they cannot write, it cannot be done. The doctor would not do it. And not just 1 doctor 2 doctors have to be involved to talk to the person and make sure that is what they want. If they cannot talk because they are so sick, then they cannot be helped. It cannot be done.

**Mr B PURANTATAMERI:** [Language.] Do not be frightened when you end up [inaudible] in hospital. [Inaudible] there is nothing ...

**General discussion in language.**

**Ms T PURUNTATAMERI:** Say when a person is in Darwin Hospital and they do not understand what is happening to them, [inaudible] ask him. If that happens, [inaudible] no longer is that person [inaudible]. They say, okay.

**Mr POOLE:** Because of the way Aboriginal society is, I do not think anybody would be making a decision like that by themselves. They would have to have their family there. That is, I think, one of the problems that Marshall Perron has with the bill. In Balanda society, in our culture, if it was me I could make that decision. Maybe I would talk to my family, but I would make the decision. In the Aboriginal culture, my understanding is that if I was sick, maybe my family would make the decision and it would be a whole discussion with everybody, if that was what was wanted.

**Mr E PURANTATAMERI:** They would still [inaudible], though.

**Mr POOLE:** Yes, that is right. One of the problems that has been explained to us is that people involved in a discussion like that maybe end up with payback.

**Dr MAYER[?]:** [Inaudible] patients not wanting to go to Darwin. [Inaudible.] We would like your reassurance [inaudible] with nursing homes and Darwin Hospital, that people are afraid of [inaudible]. That has come up quite a lot with respite care in nursing homes for the elderly. The other thing is that because of [inaudible] we cannot send as many relatives over as want to go. We can send the mothers with sick children, but if we have elderly adults we have quite a ...

**Mr POOLE:** I understand. I give you an assurance that until the bill is passed, nothing has changed, so nobody should worry about going to hospital or a nursing home in Darwin or anywhere else in the Northern Territory. Nothing has changed.

If the bill is passed, I am sure you are going to hear lots of talking in Darwin and on the television, on the radio, in the newspapers before any changes are made. Obviously, with something like this, the government is going to have to have people come out and talk to

---

everybody in language, so that they really understand what it is all about. But at the moment nothing has changed, all right? So do not be worried about going to hospital or anything like that, because I assure you nothing has changed. Any more questions?

**Mr O TIPILOURA:** [Inaudible.]

**Mr POOLE:** I shall repeat what he said. The question has been asked about people that are talking to doctors, want to make their request to have a doctor help them finish their life. This committee has already decided, as we have been travelling around, that one of the most important things would be for an interpreter to be there for Aboriginal people and for Balandas who do not speak English, so people clearly understand what their right is and what is available to them. We believe, if this bill is going to go through, it would have to have an amendment to make sure that somebody was there to interpret for people exactly what was happening, what their rights were. Any other questions?

**Mr B PURANTATAMERI:** Any other questions? Ladies?

**Mr POOLE:** Thank you all very much for coming here.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 09.30 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr B Sebastian-Pillai, Anaesthetist

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** I welcome Dr B SebastianPillai, anaesthetist, who is appearing as a witness to give evidence. Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise the committee has authorised that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case?

**Dr SEBASTIANPILLAI:** No.

**Mr POOLE:** Thank you. For the Hansard record, could you please state your full name and the capacity in which you appear today?

**Dr SEBASTIANPILLAI:** My full name is Bertram Winston SebastianPillai and I am a member of the public.

**Mr POOLE**: Thank you and welcome. What we would invite you to do, doctor, is to simply make your verbal submission to us. We can ask you some questions at the end of that time. It is really up to you. I apologise for keeping you waiting a little bit. We had a few points that we had to clear up amongst ourselves before we started.

**Dr SEBASTIANPILLAI:** When this bill was introduced by Mr Perron, I took an interest in the matter because I felt it is a matter that concerns every human being on this planet. Death is not optional. Everybody has to go through it whether we like it or not. It is very important that we spare some thought, always every day, as to how we are going to die, as much as we spend most of our time trying to determine how we are going to live.

The most important thing in this bill is how we have to die and the way we are going to die. Once you are terminally ill, when medical help is hopeless and no more, the person who is faced with death has to face his final days in an undignified manner. He is faced not only with pain but with boredom, loneliness, helplessness and the futility of life going on endlessly until death comes. This bill will help those who want to die in a dignified way.

I must mention here that, in my view, only a small percentage of people would want to take this up at this stage. That is because, in my view, it is an esoteric and sophisticated decision to want to die when your time is up.

Most of the people I have spoken to who oppose the bill are concerned that it could be abused. That is their main concern. I am here to suggest ways and means of ensuring that the bill is not abused and that it is applied correctly.

I suggest that we set up a euthanasia review board, to which all applications for euthanasia must be sent. This review board will analyse the situation and either give an okay or a refusal. Before an application is sent to the euthanasia review board, it must be supported

by a medical specialist who has diagnosed the condition as terminal. Secondly, it must be supported by a clinical psychiatrist who says that the patient is not making this request out of depression. Thirdly, the general practitioner who has been treating this patient should indicate that the request for euthanasia has been made many times to him independently. Fourthly, another GP should support that. About 3 people should have made that independent and unbiased view. In other words, 4 doctors would be required to support this view and write reports after having interviewed the patient independently. These reports would go the euthanasia review board.

The euthanasia review board would then review the application and make sure that it has been made independently, freely, rationally and without coercion. Sometimes, people who are terminally ill are desperate. They are heavily dependent on those around them and there is a risk of coercion. The patient must rely on brothers, sisters, wives, children and friends, and sometimes coercion is a very likely possibility. The purpose of the euthanasia review board is to ensure that no coercion has been applied. The board has to receive the reports of the 4 experts as well as making its own judgment.

I suggest that all people who have made an application for euthanasia should write a will. The beneficiaries in the will would have to be checked out because sometimes people who are due to inherit property might want to hasten the death of the terminally ill. I would suggest that a will be a mandatory thing for those who apply for euthanasia and that all beneficiaries should be psychoanalysed so that we make sure that no coercion has been applied. If there is any suspicion of coercion, the application for euthanasia must be refused by the review board and reasons given as to why it has been refused. The patient can then look at this, rewrite the will and make another application to the euthanasia review board for further perusal.

If the euthanasia review board still thinks that there is going to be any form of coercion by those around the person applying for euthanasia, it should try and remove the patient from that situation. The patient should be institutionalised and observed to see whether he or she still wants it. The board can then decide on allowing euthanasia or not. Those are my observations on the matter.

**Mr POOLE:** Thank you.

**Dr LIM:** Would that prolong the process, Dr Pillai? Could all the safeguards make it so lengthy that perhaps the patient will not even last that long? I mean, you are looking at a minimum of a month.

**Dr SEBASTIANPILLAI:** You see, dying can take years. Sometimes it takes months. But if the person dies in that time, the matter ends at that and for him it is solved. Sometimes it takes 6 months, 8 months, 2 months, 3 months. We have a review board that is dedicated to this and I cannot see any reason why they cannot work swiftly. As I said, applications for euthanasia will not be an avalanche. In my view, it will be just a small percentage of people.

Those who have had an active and a dynamic life and are suddenly struck down by an incurable disease find that they have lost their sense of purpose and may feel that that life is futile. They may feel that the time has come. These are the sort of people who will make an application at this stage. The review board will not have much trouble going through these things in the swiftest possible time.

**Mr STIRLING:** You have some good points there.

**Mr POOLE:** Are there any questions?

**Mr STIRLING:** Do our hospitals have ethics boards or committees?

**Dr SEBASTIANPILLAI:** Yes, we have ethics boards for research purposes. If you want to conduct clinical trials, you have to go through an ethics board to get permission. That sort of board is functioning at the moment.

**Mr STIRLING:** Might not an ethics committee or an ethics board be able to pick up these sorts of considerations?

**Dr SEBASTIANPILLAI:** We do not want doctors to be in charge of this. We want the general public to be in charge, in my view. It is not just a medical problem. It is just a day-to-day living problem. A terminally ill person is a helpless person. He cannot get out of his bed and open the door to see sunshine. He cannot turn off the light or turn the pages of a book. He is so helpless, paralysed and weak. He cannot be fed and he cannot even button his shirt. This is not a doctor's medical problem. It is a human day-to-day average problem. So let us have a review board of ordinary people who make a rational, dignified decision. When doctors come in, they talk of pain, prolongation of life and medical research. This clouds the issue. These are not medical problems. This is just an ordinary everyday problem.

**Mr POOLE:** You do not have to answer this question if you do not want to, but do you personally favour the bill? Do you think that it is a sensible idea?

**Dr SEBASTIANPILLAI:** I think there is a need for it in some situations.

**Mr STIRLING:** What sort of situations can you think of, Dr Pillai?

**Dr SEBASTIANPILLAI:** As I said, there are terminally ill people who find that they have no purpose in living any more. They feel that their time has come and they want to go. They are lonely, bored and suffering pain. Experiencing all of that put together, a small segment of the population who will choose it and it is our business to make it available to them.

**Dr LIM:** Last week we heard that, in a caring society such as the Aboriginal society, if the family and the community are there with solidarity and caring, the dying person does not feel lonely or bored or that loss of control over bodily functions is an undignified thing. In fact, those people can cope within the community very well. If you have good society, you should not have patients lying there saying: 'I am bored. I am useless, I am depending on society and therefore I should die'. You are talking about a feeling of worthlessness.

**Dr SEBASTIANPILLAI:** If that is not relevant in Aboriginal society, those people would not take up the option. It is available for somebody to take when it is needed. If the Aboriginals are not ready for it or do not need it, or their society is so good that loving care with the person who is going through the process of dying feels that it is worth doing, they will not take it up. There is no compulsion. It is just available for those who want to use it. I cannot see this issue the clouding. It is irrelevant in my view.

**Mr POOLE:** Are there any further questions?

**Mr STIRLING:** No thank you, Mr Chairman.

**Mr POOLE:** Thank you very much, doctor. It has been very interesting.

**Dr SEBASTIANPILLAI:** Thank you very much.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 09.55 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Yvonne Berecry

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

**Mr POOLE:** I call to order this hearing of the Select Committee on Euthanasia and welcome the following witness, Ms Yvonne Berecry, who is appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that the committee has authorised that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise now if that is the case? In other words, do you wish to say anything that you regard to be confidential?

**Ms BERECRY:** No it is all public.

**Mr POOLE:** Thank you. For the Hansard record, could I ask you to state your full name and the capacity in which you appear today?

**Ms BERECRY:** My name is Yvonne Berecry. I am a Catholic nun and I belong to the congregation of the Daughters of Our Lady of the Sacred Heart.

I have 20 years of nursing experience and the first 6 years of those were spent in a private hospital at Randwick, in which I nursed many people who were dying. Unfortunately, I cannot give numbers; it is too long ago. However, there were quite a lot in that first 6 years. I spent 10 years nursing and in nursing education in Papua New Guinea and from 1987 to 1993, I was chaplain at the Royal Darwin Hospital. I helped to set up the hospitalbased chaplaincy there. For the first couple of years, I worked as interchurch chaplain and for the other 4 as the Catholic chaplain. It was during that time that I became very concerned about the ways in which patients were dying in the hospital. In the early years, we had no hospice and no nursing home, so patients died in the hospital.

At that time, I heard of other concerned members of the community who were looking to get together a working party to help set up the palliative care association. I became part of that and am a foundation member of the Palliative Care Association in the Northern Territory.

During my time at the hospital, an average of 2 or 3 patients died each week and it would be a reasonable estimation to say that hardly a day went by when I did not have contact with either a terminally ill patient or their families. It is from those 13 years of experience with the dying that I wish to speak today. I will start by making a few general comments before turning to my concerns with the bill and then with the issue itself.

My first reaction, when I heard about this bill, was one of shock and disbelief. I have always had great respect for Marshall Perron and the party and it seemed to me to be quite out of character, especially the Chief Minister's attitude. It seemed to me that Marshall Perron was tremendously influenced by Helga Kruhse and Singer, and there did not seem to be any balance from the other side, from people like Dr Flemming or Brian Pollard, who could give a

balanced view. That concerned me considerably. I know that many medical personnel do not agree with the ideas of Kruhse and Singer.

This raises a big question in my mind. Is a private member's bill a device to be used by a Chief Minister to further his own personal views? According to his own admission, it was his own initiative to come forward with this bill. To me, we have a Westminster system of government. My understanding is that that is to reflect the will of the people, not to do its own bidding. I am rather surprised that there has been no inquiry in the Northern Territory into the needs of the terminally ill. I know that Queensland and South Australia, before they introduced such a bill, had an inquiry. The findings of that inquiry were the great need was for palliative care, not euthanasia.

To me, to introduce a bill without finding out the actual needs of the people concerned smacks very much of paternalism and even parliamentary arrogance. The time, I believe, for the investigation for such a very serious thing is far too short. It puts too much pressure on this committee and on the parliamentarians. I am extremely disappointed that this committee has not been given the authority to make a recommendation to the parliament.

Now, I would like to look at the bill itself. I am not a lawyer. I do not understand very much about parliamentary bills but I do know something of my medical ethics. On careful reading of this bill, I find that I have 7 real concerns.

The first relates to recognition of the complexities of the issue. I do not think that the bill addresses these well at all. In fact, it does very little. My impression from reading the bill is that it is a matter for the doctor and the patient and nobody else is involved. My experience in dealing with ill people is that this is not so. I will look at that point in more detail a bit later.

There is no mention of the right to receive adequate relief from distressing symptoms. The only solution seems to be the death of the patient.

Also, there are terms in the bill which are not clear. These include 'terminal illness' and 'distress' in clause 6(d) and 'due consideration' in clause 6(11).

What exactly is terminal illness? Most people these days, I suppose, would consider cancer and AIDS as terminal illness. But there are many medical conditions that can become terminal illnesses if they are not treated or not treated adequately. Even pneumonia can become a terminal illness. A frail aged person with pneumonia can get very sick very quickly. They will pick up very quickly if they are treated adequately. If they are left, it will become a terminal illness. Heart conditions, kidney conditions, and a whole range of diseases and conditions, can become terminal if they are not treated adequately.

What is really meant by the term 'distress' in the bill? Who gauges its intensity? I see that as open to tremendous abuse. There is no requirement for a psychologist or a psychiatrist to assess the emotional and psychological condition of the patient. Who says that the patient is in great stress? Tremendous abuse can come in there.

What is meant by 'due consideration'? From my experience, I know that a person who has just been told that they have a terminal illness will take some time to come to grips with that. It may be days, it may be weeks. During that time, it is not uncommon for a person in some way to express a wish that the whole business was over and done with. To me, that is an expression of fear of the unknown and not a specific expression that they want to be killed.

I have had many patients who have expressed, in some form or another, their desire to have the whole business over and done with. Usually that is associated with either fear in the initial stages or, later, severe pain or depression. Support the person, reaffirm their dignity as a human being, relieve their pain or their depression, and those sentiments will go. I have not found one person who did not move from that. They are then grateful that you did not take too much notice of them at the time. They often apologise and feel ashamed for saying that they wished they were dead or that somebody could have killed them.

There is no time lapse in the bill. A doctor may tell the patient today that they have a terminal illness and are not expected to live for 12 months. The patient can say straight away: 'I want to die now.' The doctor can come back the next day and say: 'Do you still feel like that?' It the answer is yes, that is the end of it. Is that due consideration? No way. But it would be covered in this bill because there is no time lapse from when the person is told they have a terminal illness until they go ahead with euthanasia.

My next point is the protection of persons who are unable to sign the certificate either for physical or emotional reasons. I am especially concerned with the emotional reasons. Again, there is no requirement for a psychologist or a psychiatrist to see the person to make any assessment as to their emotional and psychological state. I feel that it leaves it open to tremendous abuse.

In respect of deception or improper influence, how are we going to prove improper influence, given the confidential nature of the doctor/patient relationship? It might be a very subtle pressure of an attitude of the doctor or the family. You cannot measure that adequately in any way. You cannot in any way redress it later because your principal witness is dead. If the family feels that other family members or the doctor had put undue pressure on them, there can be no redress.

What about the perimeters of professional immunity? They are just so broad. There is no redress for malpractice or negligence. Again, this reduces the protection of the patient. I find it frightening. For example an elderly patient with pneumonia is very easily treated. If that is not treated, it can lead to terminal illness and death. If a doctor decided not to treat that pneumonia, all other things being equal, that is malpractice. But there is no redress in this bill. He can just go straight ahead and do that. No one has anything to fall back on and I find that frightening.

There is no restriction on the means used. A good law does not presume but we are presuming that the doctor will give the patient an injection that will painlessly put them out of their trouble. That is okay but the bill does not state that. There is nothing to stop a doctor or

somebody instructed by him to get a gun and shoot the patient. That probably would not happen but there is no restriction on it. It could happen and there would be no redress according to this bill.

Those are my 7 concerns about the bill itself. I would also like to put before you a few points on the issue itself. The first thing is the tremendous confusion in the community about what is really meant by euthanasia. Even within the medical and nursing profession, we have people getting up saying that they have helped people to die when what has actually happened is that they have turned off machines where people were actually dying or else have given large doses of morphine when a patient was in a lot of pain and that may have hastened death by some hours. That is good medical practice and has been invoked for several years.

I myself have many times been present in situations in the ICU in Royal Darwin Hospital. In those situations, after considerable consultation with the head physician or surgeon who is involved, with the nursing staff, with myself and with the family, I have been present when machines have been turned off. I am sure that there was absolutely no question in anybody's mind that that was any sort of situation of euthanasia. It was good medical practice because of the condition of the patient and the need to recognise that the patient is actually dying and that therefore the appropriate thing to do is turn off machines and allow them to die naturally. Sometimes it was 20 minutes and sometimes it was 24 hours. It was not always immediate. I find that issue very concerning.

At the moment, there are petitions circulating in the community asking people: 'Do you want the right to determine whether you will die or not? Yes or no?' In shopping centres where people are busy trying to do their weekend shopping, or in shops as you go by, young teenagers are sitting down with these things in front of them. To me, this is totally inappropriate. That is not the situation in which to ask such a profound question. The questions are ambiguous. I could say: 'Yes, I want the right to say that I will have adequate palliative care and die naturally'. I could answer yes to that or I could say: 'No, I do not want that right'. They are ambiguous and they are therefore useless polls. But they influence people and I think that is wrong.

Then there are the effects on relationships, as I mentioned before. This will have a tremendous effect on the doctor-patient relationship. It has been my experience that patients have tremendous trust in their doctors and sometimes even allow them too much power over the sort of treatment that they will have. They will not even think for themselves and say: 'Is there another alternative?' If the doctor says something, they think that it must be right. They just do not think for themselves or think that they should even ask the doctor if there is an alternative treatment.

Surely, if this bill is introduced, there will be a tremendous undermining of that relationship between the doctor and patient. I know that there would be for me personally. I would be very hesitant, if I was aged and frail and had to go into hospital. I would be really scared because, in a hospital, there is more than one doctor. There are several doctors. Although my doctor may say, 'I am there and I will treat you', there have been reported

instances where this is not enough. I mean, the doctor is not on duty 24 hours a day. Somebody else comes on and they say: 'Poor old darling, not much life left in her'. And that is the end of it, boom.

To me, that undermines the doctor-patient relationship. Marshall Perron has said: Oh no, that will not happen here, not with this bill. It has safeguards'. If it is happening now to some extent, as some are claiming, when it is a criminal offence, how does he think he is going to manage it when it is legalised? I do not know. It is a big question in my mind.

The next matter is family relationships. It will become really open for the family to put very subtle pressure on a frail aged person, that there is nothing much left for them and the best thing is to just end it all. The big question in my experience with frail aged people is dependency and their loss of autonomy. They are very vulnerable at this time to things that are suggested to them. I can see a tremendous area there. Families will put pressure on them for all sorts of economic reasons, inconvenience, selfishness. A whole string of things will really undermine family relationships.

To me, this has been a very special time with the family. When someone is dying, there can be tremendous communication and reconciliation within a family. I have been part of that many times. It not only helps the person to die with great peace and dignity; it also helps the surviving members to work through the grieving process and be better persons because of it.

Then there is the community. I consider that this will bring about tremendous changes in attitudes to the aged. Already, we have youth, vigour and accomplishment idolised. The aged are inclined to be put aside, as not having much use now. What this bill says to me is that when you are old and not able to produce and are not productive in the community, when you need care, it is a matter of: 'You are too much trouble now. You have had your day'.

It separates out a few qualities of being human and forgets the rest. It leads to uncaring attitudes, selfishness and callousness. I believe that a dramatic change will take place in society if this is brought in.

There will also be dramatic changes in the environment of the sick. All the relationships that I have just mentioned will put tremendous stress on the patient. Some people, even when they are told that they are not a bother, will not believe it because this will be part of what society is saying that when you are old and can no longer produce, you should finish it all off. I think that there are a lot of people who would feel that: 'Maybe this is what I should do. I am too much trouble to my family'. This would be a very sad situation because, as I have mentioned, this can be a very special time in a family both for the patient who is dying and for the family. Tremendous reconciliation and communication can take place at this time.

To know that the doctor has the option to end your life is not very reassuring when you are extremely vulnerable. When we see what is happening in Holland, it becomes very scary. At this point, I would like to quote from Dr Carl Gooning, who is an MD in Rotterdam. Part of his report states:

---

*Not only more and more categories of cases are added, also the numbers of cases are frightening. The government-appointed Remmelink committee reported in 1991 that on a total annual mortality of 130 000, euthanasia was applied to 2300 cases. That is not yet 2%. But the committee defines euthanasia as ending a patient's life at his request. Using the internationally-accepted definition, 'consciously causing a patient to die', we come to quite different conclusions. A recent article by the investigators of a committee showed that in almost 22 000 cases that is nearly 17% the doctor had the intention implied or explicit to end the patient's life 12 000 times without the patient's bequest.*

If that is happening in Holland, I do not see how it can be prevented from happening in Australia. I feel that it is a package deal. If you accept euthanasia, you accept that. It cannot be prevented. We have an example of what happens when we look at the question of abortion in Australia. Abortion on demand is not legal. There are varying particular situations and regulations associated with that. I know from my experience in Royal Darwin Hospital that it is virtually abortion on demand and I suspect it would be pretty much the same in the rest of Australia although I do not know. But I do know what happens in Royal Darwin Hospital.

I think one of the problems is that dignity is equated with autonomy. They are not the same. I can lose my autonomy for one reason or another. I never lose my dignity as a human being, no matter what condition I am reduced to. I have that dignity because I am. And when a couple of characteristics of a human being are picked out as the only ones that give dignity, we are in trouble. I do not have dignity because I am productive or because I am rich or because I am important. I have dignity because I am. Every person can say that.

For me, the real issue for the terminally ill is the quality of the care given, not the so-called quality of life which is bandied about in all sorts of ways. Who makes the decision on what my quality of life is and how I see the quality of life when I am terminally ill?

As I have already said, when pain and depression are relieved and treated adequately, patients want to live. There can be no real quality of care without adequate palliative care. At present in the Territory, we have 2 nurses in the district and 1 doctor, part time, for 6 months. There is no palliative care specialist. There are very limited radiotherapy services. There is a very inadequately resourced domiciliary palliative care program, and no hospice or hospicetype accommodation.

I worked for 6 weeks at Sacred Heart Hospice in Darlinghurst in Sydney during my clinical pastoral education, when I was training for chaplaincy. The atmosphere and the environment there was one of tremendous hope, peace, respect and dignity. There was really good palliative care. Patients ranged from 20yearolds dying with AIDS to elderly people dying of all sorts of things, principally cancer. After a short period of time in the hospice, each one of those people were at peace and grappling with the problems that they were facing.

---

It is very difficult for a 20yearold to die of AIDS. However, not one of those people were requesting euthanasia. That was because of the tremendous palliative care services that they were receiving. They were able to come to grips with the situation that they were facing and then to die in true dignity and peace.

I think it is interesting to note that in England, where palliative care services for the last 20 years have been tremendously developed, there is very little talk of euthanasia. It is felt to be unnecessary. On the other hand, if you go down the euthanasia road as Holland has done, there has been very little development of palliative care services.

So I believe that the Chief Minister should not be giving the doctors the licence to kill people but, rather, be providing palliative care services which truly respect the dignity of the people and assist them to die in peace supported with love to the natural end of their lives. Thank you.

**Mr POOLE:** Thank you. That was very clear and concise. I would make just one point. As much as you might like us to, we do not go through the submission and enter into all arguments. We do, however, take your points. I think you would be pleased to know that many of the points you have raised have already been raised by committee members. You have raised a couple of new issues, which is what we are all about. I simply make the point that you made in an earlier stage of your submission in commenting on Marshall Perron, the private member's bill and the CLP. It most definitely is not a CLP initiative. It is his personal initiative. We are treating it in that way which is why we have a bipartisan committee looking at it. There is a fair amount of division in both parties, I think. Are there any questions?

**Dr LIM:** Some doctors and a lot of patients would say that euthanasia in fact improves the doctor patient relationship in the sense that the patient has the full modalities of treatment right from the beginning to the very end. The doctor actually follows the patient right through the whole process, from good health to poor health to dying. According to this view, the ability to provide euthanasia is the one last act in the good doctorpatient relationship. You are actually helping a patient who is in quite significant distress, when all else has failed. Can you rationalise that for me?

**Ms BERECRY:** If a patient is given good palliative care, they will not be in great distress. The 2 key areas are pain and depression. Among the hundreds of patients I have dealt with or been aware of, none wanted euthanasia when the pain and the depression were controlled. When they were in severe pain or severely depressed, some of them expressed a wish to end the whole jolly show. That is what I am saying. When those conditions are controlled, the natural desire to live life to the end comes forth. There is a certain something that most people come back to when they are dying. It is the natural thing to do. They may not express it in that way but there is something within the person. It is when they are very distressed from pain or depression that they just want an out, which is pretty normal. Control that and they spring up again. I have seen it time and time again. They even say: 'Thank you for not listening to me at that time. I want to live again'. It may be there in some people but I have never come across it in my time. That is all I can say.

---

**Mr STIRLING:** We have heard much on the question of palliative care as the committee has travelled around the Territory. I can assure you that it will be a strong part of the report. There is a need to look at the needs of the terminally ill. The whole palliative care issue has to be addressed and given the proper resources that are required. I was interested in your comment that this committee had no power to make any recommendation. That is not the case. This committee is within its own power as to what form its report takes and what it states. I am not sure how you understood that?

**Ms BERECRY:** There was nothing in the terms of reference that said that you had the power to make recommendations to parliament.

**Mr POOLE:** We tend to be like most parliamentarians and utilise the unwritten word rather than the written word on things like that. We will certainly be making a report to the parliament. Now, whether or not ...

**Ms BERECRY:** But a report is not a recommendation, is it?

**Mr POOLE:** The report will contain a number of recommendations.

**Ms BERECRY:** Recommendations, I see. Thank you for that.

**Mr POOLE:** Now, we are not there to recommend to the parliament that the bill go through or not go through. We are there to recommend whether it is a good bill technically or is poorly drafted. We can highlight areas that we feel need to be addressed.

**Ms BERECRY:** I think that was the key area. Whether the bill should go through or not is another thing. You have not got the power to say ...

**Mr POOLE:** I guess, if we decided amongst ourselves, we could. We probably would not because we probably would not all agree.

**Ms BERECRY:** No, right.

**Mr POOLE:** I think the duty we have to the people of the Northern Territory and to the parliament is to make sure that everybody is aware of the pros and the cons and that they are properly debated so everybody does that from an informed position. We have already picked up things like the 12 month period, the possible need for a coolingoff period, those sorts of things. We have not come to a firm decision on them but they are all points that we will be talking about by ourselves in the committee process.

**Ms BERECRY:** Yes, I see. Thank you for that.

**Mr POOLE:** Well, thank you very much for appearing today. It was very clear and concise. Thank you.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 10.40 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Professor Michael Ashby, Consultant Physician

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

1

---

**Mr POOLE:** I call to order this hearing of the Select Committee on Euthanasia and welcome Professor Michael Ashby, Director of Palliative Medicine and Radiation Oncologist, Royal Adelaide Hospital, who is appearing as a witness to give evidence.

Other than in exceptional circumstances witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that the committee has authorised, for the purposes of this inquiry, that the usual proscription on the disclosure or publication on material placed the committee does not apply.

Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise us now if that is the case.

**Professor ASHBY**: There is no requirement on my part.

**Mr POOLE**: Thank you. For the Hansard record, could I ask you to state your full name and the capacity in which you appear today.

**Professor ASHBY**: Thank you. There has been a change of detail in that I have moved from Adelaide to Melbourne. My name is Professor Michael Ashby. I am a consultant physician and a Fellow of the Royal Australasian College of Physicians. My present post is Professor and Director of Palliative Care, Monash University based at the Monash Medical Centre in Clayton, Victoria.

**Mr POOLE**: Thank you very much. Professor, what we have been doing so far with witnesses is allowing them to speak to the committee, to make whatever submission they want to make. We then go into a question and answer format. We have allowed a fair length of time, so it is really up to you as to how much of that time we utilise.

**Professor ASHBY**: Perhaps the easiest thing for me to do at this point would be to say that I was involved with the drafting of a policy statement on voluntary active euthanasia for the Australian Association for Hospice and Palliative Care. I do not appear today as a spokesperson for that. Indeed, I hold no elected office in that organisation at the present time although I have in the past. I was requested by their executive to produce a discussion document and a draft policy. That has now been adopted in Victoria and I think is well on the way in other states and territories. As I was responsible for drafting that policy statement, it might perhaps be helpful if I briefly go over it because it does broadly define my viewpoint on this issue.

What we set out to do first of all was to define hospice and palliative care as a concept of care which provides coordinated medical, nursing and allied services for people who are terminally ill to live where possible in the environment of their choice, and which provides physical, psychological, emotional and spiritual support for patients and for patients' families and friends. The provision of hospice and palliative care services includes grief and bereavement support for family and other carers during the life of the patient, continuing after

---

death. We have defined voluntary active euthanasia as the deliberate action to terminate life by someone other than and at the request of the patient concerned. We believe that dying is a natural process and that the refusal or withdrawal of futile treatment is not voluntary active euthanasia.

We believe that legalisation of voluntary active euthanasia is not a substitute for the provision of palliative care services to all Australians. We believe that public interest in voluntary active euthanasia reflects concern about lack of adequate support for people who are dying and will continue to campaign for improved services, education and research in all aspects of palliative care. We state that currently accepted palliative care practice does not include deliberate ending of life even if this is requested by the patient. We assert that palliative care experience shows that the skilled adjustment of a morphine dose for pain relief does not cause death.

We recognise that there is a wide divergence of views about voluntary active euthanasia in Australian society and also within the caring professions including the palliative care community. We recognise and respect the fact that some people rationally and consistently request voluntary active euthanasia. We acknowledge that, while pain and symptoms can be addressed, complete relief is not always possible in all cases even with optimal palliative care. We welcome open and frank discussion within the community and particularly within the health care professions about all aspects of death and dying including voluntary active euthanasia.

You will seen from that that the position emerging amongst palliative care workers in Australia is that many of us now want to remove our specialist or subspecialist area of medical or nursing multidisciplinary practice out of the debate in a sense of not going to bat for one side or the other in a polar debate about voluntary active euthanasia. We believe that, when requested, we should provide committees like this with the information that you need about what we really do and what our intentions really are in the manner in which we treat our patients.

It would be wrong of us to use our skills and our special knowledge and experience on one side or other of the societal debate. I do not believe that it is any longer appropriate for palliative care workers to suggest that they can control all patients' pain, or that they can give meaning to the end of life when the patient feels that their quality of life is so poor that they do not wish to live any longer. I do not think that any professional person should be in the business of saying they can always turn that around and make what the person would want.

Just as palliative care is predicated on recognising the limitations of medicine and addressing the care needs of the patient when cure is no longer possible, so too we in palliative care have to recognise our own limitations. These include clinical limitation, and human and spiritual limitations. This includes recognising that some of our patients do wish to die and say so consistently.

---

Having said that, it is a relatively infrequent occurrence. In my experience, it would happen a handful of times a year maybe 10 or 20 but no more. Most of those requests are modified a few days later by a change in the circumstances, either through symptom control, better emotional and psychological adjustment to the situation, or maybe some readjustment of family dynamics or support that was not apparent before.

However, I have to say that there are a few patients for whom that is definitely not the case. On a recent study tour last year to Canada, I came across the story of Sue Rodriguez. I believe that you have already received references to that Canadian case. I actually read the judgement. As a doctor, reading a legal case was quite a challenge. But it certainly assisted me greatly in my personal deliberations on the subject. I have submitted a copy of the full judgement to this committee to be photocopied and placed in evidence before you.

There is a book whose details I would like to place on the record for reference. It is Birnie L. and Rodriguez S. *Uncommon Will The Death of Sue Rodriguez* (Toronto, Macmillan, Canada 1994). I do not think it is available in Australia at the present time. It is the authorised biography of Sue Rodriguez. I was particularly struck by the fact that she states on a number of occasions that the palliative care services in her area are not helping her in achieving what she seeks and she therefore distances herself from them. I think that we have to hear that there would certainly be a small part of our community here in Australia which would probably feel the same way.

It is also perhaps worth both pointing out that in many documented cases of medical assistance in dying, the patient is not actually terminally ill at the time of the request. Indeed, the reasons for making such a request may well not be just the objective tests of uncontrolled pain and suffering. There may be chronic disability or in some cases chronic mental distress, areas in which palliative care as such is very poorly equipped to assist. That is not to say that we would not try to help if such people are referred to our services. Obviously, however, in an area such as mental health, that lies completely outside the field unless the person has a terminal illness.

To just round off my verbal evidence today to you, which I will keep brief, I will say that I think there are many of us in palliative care who, if we were in your assembly when the bill came before us, would probably abstain rather than vote against it. I am speaking here as an individual and not for any organisation which employs me or of whom I am a member. My personal reason for doing that is that I think that I have no good argument against the kind of arguments that were put forward by Max Charlesworth in his recent book, *Bioethics in a Liberal Democratic Society* (Cambridge 1993). Charlesworth says that he can come up with no good argument in a liberal democratic society against individuals who consistently request active help in ending their lives. He could find no good argument not to allow them that right. As a palliative care practitioner and as an individual, I do not feel that I have any good arguments against that position.

That having been said, the really important issue for me is my professional role. Given my role as a professor of palliative care, one of a small number of people in Australia in that kind of academic position, I have to say to you that there still remains a lot to do in palliative care. I am sure you have already heard this more times than you want to hear it.

---

Here in the Territory, by virtue of distance, I suspect that a lot of patients do not receive optimal palliative care. The Northern Territory is not alone in that. There are many areas where the tyranny of distance does not rule and where, for other reasons, palliative care is not being delivered adequately. Coverage around this country is still patchy and indeed it is patchy in all countries. I do not think Australia should feel particularly singled out and I am sure that is not the case.

If you are a medical practitioner aged approximately 35 years or more, it is highly unlikely that you had any adequate undergraduate teaching in this area. It is possible, in fact highly probable, that your medical school had no curriculum to deal with chronic pain. I think that the reason for this was that medicine until very recently was solely focused on curative endeavours and all other endeavours were regarded as somehow disappointing, second rate and not worthy of scholarly and professional attention. I can still remember days in my own medical school in London in the late 1970's when doctors would regularly with the best of intentions lie to their patients in euphemistic ways, particularly about a cancer diagnosis, would not speak openly about death and dying, and would uneasily move away from the bedside of a dying patient because they did not know what to say or what to do.

You will hear from others before this committee and probably have already heard a considerable amount about the history of the hospice movement in the United Kingdom. It has spread right around the world, which has been a very remarkable change in focus of medical attention in the period of just over 25 years. There has been quite a dramatic change. However, the movement is not universal. For example, I do not think there is a single academic position in palliative care in a medical school in the United States of America. There are a few people with an interest but they do not actually put it up front. I know of one major US health care institution which will not allow its world class pain unit to be renamed a palliative care unit because that is not in the philosophy of the institution.

That is certainly not the case here in Australia. I am pleased to see increasing recognition for palliative at all levels of society and I believe that it has received good support from governments in this country. However, I believe that here in the Territory there are some important provisions to be addressed, notably the provision of dedicated beds. I do not believe it is necessary for it to be an expensive, free-standing, separate hospice facility. Indeed, given the population distribution and demographics of the Territory, and there will be something to be said for the beds actually being located in small strategic numbers in the major hospitals of the Territory.

Obviously, there is an urgent need to make sure that community medical and nursing skills are nurtured and supported so that people can die in comfort and dignity in the far flung corners of this Territory. Certainly, it is a deficiency in my view, for instance, that at the moment it would be very difficult for a specialised palliative care nurse to go to an outback location. He or she would have to vacate their position here in Darwin to do that. Some backup to be able to do that would be cost effective and would greatly assist in the care of the dying.

5

---

Without going into my view of how palliative care could be better done in the Territory in detail, which you would not necessarily want to hear, I think that there are areas of endeavour to be looked at. If the process of reviewing the bill allows a comprehensive review and improvement of palliative care facilities here in the Territory, that in its own right will be a very significant achievement which this Assembly could take pride in. If, however, the bill is just viewed as the matter in hand, the worst scenario of all in my view would be for the parliament to pass it and do nothing about palliative care. To do that would be to do itself and its community a grave disservice. The scrutiny of the rest of Australia and the world would shine very sharply on this Territory and I would suspect that there would be a lot of negative consequences.

I think I will leave it there. Now I would be pleased to answer any questions or hear any points that you want to make to me.

**Mr POOLE**: If I hear you correctly, even if we did live in an ideal world and the Northern Territory had palliative care facilities ranked with the best in the world, at the end of the day a small percentage of people still would not be kept in a comfortable or tolerable state by palliative care services and might well request assistance to end their lives anyway.

**Professor ASHBY**: I believe that to be a true statement.

**Mr POOLE:** You said only a handful of people, perhaps half a dozen or so in your personal experience, ask for that. Some of those obviously change their mind because of changes in their mental state or their physical condition. What total numbers are you talking about? Are you talking about a couple of hundred patients or ...?

**Professor ASHBY**: No. I would be talking about my experience in my last position, which I only recently left. We were getting approximately 800 referrals a year. Of course, as you will see in your evidence, people do not necessarily ask their doctor for assistance in dying. They may well feel that that person would be affronted or offended, or that there may be some legal implications. However, over the last few years since I came back to Australia in 1989, I have found that more and more people now are saying openly that they wish they did not have to go through the last bit of the illness. Gradually, patients themselves and families are talking much more openly about it. I think there was a feeling, particularly if you were in a Catholic health care institution, that you should not even mention the words.

If somebody raises the issue with me in a covert and subtle way, subject to the sensitivity of the circumstances, I would actually tease out what they are driving at and actually name the words. I would ask them: 'Are you talking here about voluntary active euthanasia? Do you want me to help you to die?' I think that if you can actually clarify what the person wants, we can have a conversation about what I can and cannot do and what their reasons for that might be. We can acknowledge that this is not an ideal world and we do not always get what we want. The idea that, in some cases, we can somehow sanitise and medicalise death and turn it into some kind of calm, peaceful event is probably seeking too much control.

I think that is a major issue for those of us who are the tail end of the baby boomers or the me generation, or whatever you care to call it. We are really used to having incredible control over our own destinies. We have a strong investment in our careers, our choices and our rights. I am not saying that that is bad. Most of us would say that it is a defining aspect of our existence that we are lucky enough to live in a time and a society where we have probably never had better recognition of our rights and probably never had more control over our choices in life. But the idea that we have control over everything is quite illusionary. It really is a transient illusion, and I suspect that it will be looked back on with some amusement by future generations, that somehow we can make the last bit of our lives as full of choices as the rest of our lives. I think that is fatally flawed.

I went to a meeting recently in Canada. One of the Canadians joked about the United States and said: 'I get the impression that, south of the border, there is a widespread view that death is optional'.

**Mr STIRLING**: Professor, I think that is a very interesting point. We have often said that the baby boom is a very selfish generation in Australia. By virtue of its size, it is able to dominate everything that is going on. It is interesting to speculate that this drive for choice may well have arisen from that. However, I want to refer to the Rodriguez case. She was suffering ALS which I took or understood to be some sort of MS.

**Professor ASHBY**: No, it is not. ALS is a form of motor neurone disease. In the US, it is known as Lou Gehrig's disease. That is like saying it is O J Simpson's disease. Lou Gehrig was a very famous baseballer. Everywhere in North America you will hear it referred to as that. ALS is just Amyotrophic Lateral Sclerosis, which is an old fashioned name for what the neuropathologists saw down the microscope when they dissected the nervous tissue of people who had died of this condition. The best term to use is Motor Neurone Disease or MND for short. Everybody in Australia will then know what you mean. There is an MND Society of Australia, which is the national association for patients and families.

It is a rare condition. If you want to know any more about its care in Australia, one of the places that particularly specialises in it is Bethlehem Hospital in Caulfield, Melbourne, close to where I am now working.

The feature of this disease is that it can have a very variable natural history. One of the longest stable sufferers is Stephen Hawking. A colleague of mine recently died of the condition within a few months in Adelaide, and that was a devastating course. It gradually robs the person of virtually all neurological function. Particularly early in the piece, it can interfere with speech and swallowing. It is quite a hideous way to die. Multiple Sclerosis can do the same thing incidentally, and a number of other neurological conditions can lead to the slow physical disintegration of person with comparative sparing of mental function.

What Sue Rodriguez was saying and I really think her arguments were very powerful although the legal basis for it is more questionable and outside my area of expertise was that she did not want to go through the last bit, even if she was not aware of it. She said: 'The

reason for that is that I do not want my 9 year old son to see it and I do not want my estranged husband to have to witness, even if I never know anything about it. It has no meaning to me. I want to say that up front and now because I know that, when I get there, I will be able to say nothing about it.

**Mr STIRLING**: This is the dilemma.

**Professor ASHBY**: It is the dilemma. I do not believe that any hospice or palliative care organisation could honestly say that they had a good answer for Sue Rodriguez' dilemma. As you know, she took it all the way to the top of the Supreme Court of Canada and she won very substantial sympathy. If you look at those judgements and read between the lines and the Chief Justice of British Columbia and the Chief Justice of the Supreme Court of Canada both voted in her favour and gave dissenting judgements in her favour you can see, according to my interpretation of what they are saying, that they would really like to help this woman and on humanitarian grounds they actually agree that it is reasonable for her to have a lethal injection.

However, given that the case was framed in certain legal terms, how were they to get to the outcome that they would have liked to see? The tried many convoluted legal arguments to try to get from that point to this. (Reference: Rodriguez v BC (A.G.) [1993]3 SCR)

I think that happened in the Bland case too. No doubt you have received evidence about the House of Lords appeal decision in the case of Airedale and AHS Trust versus Bland in the UK. Similarly, you can see enormous sympathy from the judges on the bench for the dilemma that the family and the doctors are in. You can almost see them trying to make the legal deliberative process come to the conclusion that they would like to see from a human perspective. (Reference: Airedale NHS Trust v Bland [1993]1 All ER 801-896)

**Mr POOLE**: Looking at the Northern Territory from a current palliative care point of view, I guess it would be reasonable to assume that no matter what we did as a government, you would only ever expect to see palliative care centres in Alice Springs, Darwin and possibly larger centres such as Katherine and Tennant Creek. You would never see them in small settlements of a couple of hundred people. What sort of numbers are there in palliative care services in the larger centres down south. In a place such as Adelaide, are there 400 beds or 50 beds, for example? I am just trying to get some equation in terms of the population of the Territory.

**Professor ASHBY**: I am afraid that I do not have the precise bed numbers for metropolitan Adelaide. If you wish, I can provide that as separate written evidence or ask one of my Adelaide colleagues to do so. The Australian Association for Hospice and Palliative Care has a ideal figure which, if I recall correctly, is 50 beds per million of the population. Again, I would like the opportunity to cross check that. The association could submit it in evidence to you. In fact, if you have not received a formal submission from them, I think it would be important for you to request one and particularly to flag that kind of issue to ensure those figures are accurate. I am sure that can be done without any problem.

---

**Mr POOLE**: Using those figures as a rough guideline, are you basically saying that that is a sensible figure and the needs for palliative care, for example, in New South Wales are reasonably well serviced? Or would you say that they should have far more beds in an ideal world.

**Professor ASHBY**: I think it is not so much a question of bed number as bed distribution and bed function. If you are looking at acute hospice care, which is what I have mainly been involved in, I would say that for a community of the size of the Top End say the greater Darwin area and the areas that it serves, possibly extending as far as Katherine and Tennant Creek you would probably be looking at somewhere between 6 and 8 beds for specific symptom and pain control where patients could be sent for complex problems. I would suggest that that would be in the hospital, so that you could tap into all the resources and scales of economy that you get by being in a hospital rather than being in a freestanding site.

Respite, however, obviously has to be closer to the patient's home. So it might be important to have 1 or 2 beds designated, if not dedicated, in the other hospitals in the Territory. I guess you would be looking at Tennant Creek and Katherine, and naturally Alice Springs. You should have some designated beds and a skill base or area in the hospital where a patient with palliative care needs can go for respite or symptom control for that matter. It will not always be realistic or appropriate to fly very sick people or drive them long distances in the Territory.

The issue is not so much bed numbers as the skills that exist when the person gets there. I have seen this as a problem in a number of isolated regional centres in rural Australia. A palliative care room is put in and a lot is invested in the fabric. They make a lovely room and no doubt it is great. But then you ask: 'What kind of expertise is there? Do you have anybody who is really good at cancer pain relief on the staff?' The answer may well be: 'We do not actually have anybody with that particular interest.'

**Mr POOLE**: That is actually the situation in Alice Springs. Whilst the room is there, they really do not have the staff to provide the services.

**Professor ASHBY**: That is right. I am familiar with that situation. The anaesthetist who is director of intensive care is just so busy with desperately sick people on ITU and going to cardiac arrests and so forth. It is unreasonable to expect a person in that role to be able to give an hour or two a day to looking after palliative care patients, liaising with community workers and trying to put in a palliative care service. Obviously, there is some valuable work going on there, but when you are that busy and doing other things that will inevitably be more pressing, it does not work very well.

**Mr POOLE**: And as a general rule, are these people available? When you are involved with government in the Territory, you hear quite a lot about the difficulty of getting doctors to go to the more isolated areas. I am sure that the outback areas of New South Wales, South Australia and Victoria probably have the same problems. Are there people

available if you did go down that road, who could be slotted in reasonably easily? Or is there a great shortage of palliative care providers from a doctor's point of view in Australia?

**Professor ASHBY**: You framed the question entirely appropriately to the answer. No, there are not. It is well known that it has been difficult to fill palliative care posts in the major cities. In the northern area of Adelaide, there have been enormous problems in finding a medical director. There are sessional appointments at several Melbourne hospitals where the field of candidates has not been large. So, I just do not think that is the way you can possibly approach it here in the Territory.

What we need is a network which practitioners can actually plug into easily, and more training. Education is almost an insulting word, as if the doctors do not know how to look after their patients. Most doctors do have some of the basic skills. However, if they were never taught how to do it at medical school, there will inevitably be some gaps. These are best filled, I think, by a good collaboration without you looking after a patient. They actually first need to recognise that there is a problem.

I have been involved in seminars up here in the Territory. I have given a number of talks, and I actually see the same faces there all the time. They are all the people who are doing it wonderfully well already. There are a number of GPs in this city who have what I would call a significant interest in palliative care and are already doing it very well. The problem arises when a patient is being cared for by a doctor, who through no fault of his or her own, has been trained in the era when medical education did not even look at the area. Such people may feel somewhat affronted by the challenge that they are not actually doing as well as they might.

I feel that it would be important for an organisation like the AMA to say: 'Right, we need to recognise this as a responsibility. All of our members need to acquire some competency in this area'. I put it to you that, if it was a new cardiac technique, the skilling would be rapid. It would be considered to be almost culpable negligence if you did not know about a major new development in the treatment of heart disease, let us say. If you were found, in a small town here in the Northern Territory, not to be referring your patients for coronary artery surgery when they have severe angina, somebody would ask a question somewhere along the line, saying: 'You are really behind the eight ball here. What are you doing?'

It does not seem to be like that in palliative care. Somehow it is not deemed important enough. I think all of us in professions have a tendency to feel a little confronted and angry when the torch is shone on our ignorance. We do not like it. It dents the model, the mould, the image. I think my profession is the same as any other and I suspect that I am like that too. None of us like having our deficiencies pointed out.

**Mr POOLE**: My interpretation of what you said in relation to pain management was that, because of lack of training I presume, pain relieving substances are sometimes given and as a result of increasing the patient's tolerance level and the increased dosage, the side effect

can be that the patient actually dies. We have had comment made by doctors and nurses that this does happen but it has always been stressed that the intention is to give pain relief rather than to actively kill the person. There are cases around Australia, as in Victoria, where doctors are springing up out of the woodwork and saying that they have done it. Do you think that a lot of that that goes on?

**Professor ASHBY**: How would one know? You have probably come across the Remmelink Report from the Netherlands. (See Van der Mans P.J., Van Delden J.J.M., Pijnenborgh et al. Euthanasia and other medical decisions concerning the end of life. Lancet 1991; 338:669-674.) When you start to ask doctors how they treat patients at the end of life, the main methodology has just been to say: 'What did you think you were doing; what were your intentions?' There is no way of validating that. There is no way that you can find out what they really meant or really did, unless you went back to the cases and looked at all the records blow by blow and milligram by milligram. You may on occasions find that they stated to you that they wanted to actively end a patient's life and you find that they increased the morphine dose from 5 to 500 in one day. It might be transparent as to what they intended.

I put it to you that, in actual fact, when you analyse all of these surveys, studies and cases, in a small number the intention was active ending of life. However, if you look at the Remmelink Report, the data is very deceiving. The doctors said that they have actively ended life when they stopped treatment that was not working any more. Here in Australia, we would tend to regard that as normal and sensible medical practice. Yet they are saying that it is some kind of active decision at the end of life, which brought about the death of the patient.

Equally with opioid analgesia with morphine you hear an awful lot. There is a very long tradition, in legal judgments and in committees of this sort, that there is some kind of dose of morphine where the danger of death becomes paramount and that there is some kind of conflict going on between pain relief and active ending of life. I really do not believe that to be the case.

There are other drugs used to sedate patients because they are confused, agitated or distressed in some way where the line might be finer with regard to the cause or timing of death. But I do not think that is a conflict with morphine. I think we need to lay to rest this ghost of the large dose of morphine that causes death. You escalate up to the dose that the patient needs for comfort. If, as I said you move from 5 milligrams to 500 milligrams 4 hourly in one step, it is obvious what you are trying to do. We have worked out steps of increasing the dose and titrating it against the patient's level of pain. Although it sounds very scientific, it is more of a clinical art. There is some science in there but we do not understand it. For some reason, the level of pain balances out the side effects of morphine that might be seen to be life ending, such as respiratory depression.

**Mr POOLE**: It has been described by a good doctor, who is a member of our committee, as a window which gets narrower and narrower as you increase the dosage. Occasionally, I guess people cross the line and the patients die.

**Professor ASHBY**: I do not think that is a common occurrence in the good practice of palliative care.

---

**Mr POOLE**: That is an interesting statement. You are saying that, when that happens, more often than not despite the protestations of the good doctors, in actual fact the intention is to kill the patient.

**Professor ASHBY**: No, I do not think that is what I am actually saying. If you ask doctors what they thought they were doing in a particular situation, some of them will say: 'That dose of morphine killed the patient. I gave it and I am comfortable with that because I was trying to relieve pain'. I would have to see those doses and the charts before I could actually comment. But I wonder whether they really are doing that when they say they are. I suspect that often they are not. On the odd occasion, I am perfectly willing to accept that they have given very large stepups in doses with an obvious intention of actively ending life. I am not saying that it does not happen but I would not want that to be seen to be a kind of everyday occurrence and a dilemma and problem for the practice of palliative care. It is not.

**Dr LIM**: If I can explain a bit more, I was talking about the window of safety of increasing any therapeutic drug where, as the level of pain increases, the level of complications from medication would increase. Therefore your window of safety in effect gets narrower and narrower. However, we are never sure of where the line is in terms of tipping a patient over into dying. If you can achieve the window of safety, so much the better. But the moment may come where in fact your level or dosage is in fact the dosage which tips the patient over.

**Professor ASHBY**: I do not think the window becomes narrower as the dose goes on. In fact, the time when you might be most vulnerable to serious side effects is your very first dose of morphine. Let us say that you are an elderly person in your 90s with an undiagnosed mild renal failure. If you have 10 milligrams of morphine, I would put it to you that you would be more vulnerable to respiratory depression after that first dose than you would if you started on it and you got up to 35 milligrams 4 hourly by step-wise increases to the dose and titration against your pain levels. So I am not sure that the window necessarily does narrow quite as you suggest. I do not think we have a lot of good information, to be honest.

To respond to your second comment about the line being a fine one in palliative care, the answer is yes. It is often fine. With palliative care interventions, I think that we probably both increase and shorten life in different situations and it is often not possible for us to predict how. I have seen people who have come in looking almost moribund. You find out that pain is the real issue. You relieve the pain and they actually go on for many more weeks. Equally some patients start on morphine, get fairly rapid pain relief and just fall asleep and die. Sometimes, the relief of pain is like the relieving of a large burden and almost a stimulus to stay alive. For some people, laying down that burden is just such a relief. That is a very subjective remark but I have actually seen it happen a number of times.

I was referring to the Remmelink Report and I wonder if I could just quote from a paper that I am in the process of writing. It is about what doctors report in medical decisions at the end of life. I talk about the potential for misinterpretation of the data categories in studies such as the Remmelink Report from the Netherlands:

---

*In a study of doctor's opinions about the nature of their clinical decision making for dying patients, 38% of 9250 deaths studied involved a medical decision at the end of life, or MDEL. But true reported acts of voluntary active euthanasia constituted only 1.8% of cases. Considerable concern has been expressed about the 0.8% who report as being subject to that of nonvoluntary euthanasia, although as it turns out nearly all of these have previously discussed euthanasia with their doctors, were terminally ill and incompetent. (Organic brain dysfunction is a very common problem in terminal care, see Bruera and Wood et al).* (Reference Bruera E. Cognitive failure in patients with terminal cancer: a prospective study. J Pain Symptom Management 1992; 7:192-5.)

*Concerns have also been expressed that cases of VAE are not reported and this may conceal acts of nonvoluntary euthanasia, although this is not an exclusively Dutch problem. The vast majority of reported MDELs 35% were either nontreatment decisions, the withholding or withdrawal of treatment in situations where the treatment could have prolonged life 17½% or alleviation of pain and symptoms with opioids and such doses that the patient's life might have been shortened 17½% of cases.*

*Allocation of patients to these categories was determined by the doctor's opinions about the supposed consequences of their management. The majority of these decisions can probably be located in the domain of good palliative care practice and the authors were careful to avoid the conflationary term of 'passive euthanasia'. In particular the notion that 'large doses of opioids cause death' per se is flawed, although the use of large initial doses in opioid naive patients or large dose increases in patients who are on regular opioid analgesia regimes may reveal an intent to end life rather than relieve pain, and as such would not be considered to be part of palliative care practice.*

**Mr POOLE**: In debate before this committee, it has been argued in support of the bill that it would be preferable in our society to at least know what is going on and that is a good reason to allow euthanasia. At least we would know, presumably, the number of patients per annum who were dying, how they were dying and so on. Do you wish to comment on that?

**Professor ASHBY**: Well, let us take a parallel situation. Domestic violence is something that until recently we did not know very much about. Most of it went on in the privacy of people's homes and it was only when it spilt out into the street or a body emerged that the police were involved. Nobody suggested that, as a way of gathering information about domestic violence, we should actually legalise it. So I think that argument is totally flawed. You might say that backyard abortion is a better analogy. When it was illegal, it was still performed regardless of the legal penalties. It had always been performed. By legalising it, you brought it out into the open and the safety of women was far better protected. I am not sure that those arguments hold sway in quite the same way in the issue of voluntary active euthanasia. I think that would be a poor motive to change the law.

---

**Dr LIM**: One of the comments made recently about the policy of the Australian Association of Hospice and Palliative Care is that there is a softening of its attitude towards euthanasia. Is there a softening? Is the association shifting towards a position which is more likely to assist patients requesting euthanasia?

**Professor ASHBY**: The answer is no. This policy statement is intended to be a conciliatory policy that helps the Australian community to see where its palliative care practitioners stand. It shows tolerance for all viewpoints including all religious and moral viewpoints.

I would have to say that the process of drafting this document met with a considerable amount of concern amongst my colleagues that it be seen to be a softening of the line that palliative care as presently practised did not include the active ending of life. We obviously had to make that clear in the drafting of the policy, and we did.

I think it would be fair to say the majority of my colleagues in this country are opposed to the bill that has been put before your Assembly. For many of them, that is based on a personal and usually Christian religious worldview. For others, it is a matter of individual medical ethics and what they see as the tradition of the ethical basis of their profession. There would be very few members of this association who approve of the legalisation of voluntary active euthanasia as proposed before this Assembly.

I do not believe that they have changed their line but what I have sought to do, with a considerable amount of support in the organisation, is to achieve a situation in which we do not use our skills and knowledge, and our privileged position in society, to actively campaign for or against. We hope that this debate will improve the care of dying people regardless of what is put on the statute books of the Northern Territory. I would have to say that a substantial majority of the members of this association, be they medical practitioners, nurses, allied and other health care professionals and volunteers, would be opposed to Mr Perron's bill. That is not to say that there would not be an increasing number, as in the community, who support it or would not be opposed to it. I do not think there is anybody in our association who thinks it is the major issue.

**Dr LIM**: We talk about some patients who would never be able to obtain adequate relief of their pain and suffering through palliative care. What do you do with them if they ask that they should be given access to euthanasia? What do you do with them?

**Professor ASHBY**: That is a fair question. From a medical colleague, I accept it in good part that I can be faced with a practical situation where my rhetoric and my position as presented to you today presents a gap between what the patient is requesting and appears to need, and what I have said I will provide and what the law allows me to provide. So what do I do?

I think the first thing is to recognise the request as a reasonable and sane request. Clinically, you obviously need to see whether depression is present. You need to see whether

---

there is some aspect of the person's medical care or of personal support mechanisms which you can assist to put right or to improve for them. Having done that, you may still be faced with somebody who is making a persistent request.

Perhaps I can give you a case history which is obviously scrambled so it cannot be identified on the public record. It occurred in another jurisdiction. A young woman, who had very advanced metastatic cancer in her chest, was severely short of breath at rest. She had 2 young children and a mother who came from a European country which had made any thought of active assistance in dying quite repugnant to her. I will not identify that country but you can imagine a few options that would readily come to mind. The husband was supportive of the woman's request.

She came into the hospice at which I was working and really bailed me up. She said: 'Look, you can see how short of breath I am at the moment. With oxygen and a bit of radiotherapy to this lumbar that is pressing on my trachea, I will probably be all right to get home. But I know this is going to get worse. It is at the limit of my tolerance at the moment and it is just about getting to the limit of your capacity as a medical practitioner to control the symptoms. When it gets beyond that, I want to die'.

We worked through what it was that she feared. It was not difficult to do that. She obviously feared being uncontrollably short of breath as she died in front of her family, feeling that she was drowning. She feared that that would occur at home and there would be no assistance to her, and that she might spend even a few minutes, which would certainly be too long, in that condition. Worse still, she might spend a few hours in that state, which would be just grotesque.

What I did was to explain to her the limitations that I felt were in front of me. I said that, if she was getting towards a stage where that happened, I would be happy to supply and if need be administer medication that would make her unaware of that condition. I said that there may be a fine line in terms of the timing of her death but that I did not believe I would be changing the cause of it, and that I believed that no judge, no jury and no parliament would want to deny me making her unconscious during that dying process.

In fact, that did happen. I was called to the house some weeks later. As a result of palliative care intervention, she did actually have a time that, without being able to be described as comfortable, was acceptable to her. It was a precious time with the children at home.

When she felt she was going under for the third time, she actually put her hand up and said: 'Can you come out here?' I went out there. She was already receiving morphine and I increased her morphine dose, although not by a large amount. I actually increased the dose of a sedative drug in her subcutaneous syringe driver, to a level where she became much more sleepy and indicated that she was comfortable. I also wrote up topup doses so that, if she woke up in agitation, there would be a fairly sizeable dose that would hopefully make her unconscious in a few moments. Therein lies your fine line. It is a fine line. Roger Hunt will talk to you a bit more about that because he has actually written about it.

---

**Dr LIM**: The question is, then, if you were to put a patient into an unconscious state, what is the difference between that and euthanasia?

**Professor ASHBY**: Between that and voluntary active euthanasia? I would say ...

**Dr LIM**: Voluntary requested euthanasia.

**Professor ASHBY**: I keep coming back to that because I think it is important to have one clear definition. It stops this public debate being hijacked into all kinds of other totally unfruitful areas such as Nazi Germany and so forth, if we are clear that it is voluntary active assistance in dying. When I say there is a fine line, I believe that I have possibly affected the timing of the death. That is why I said what I did then.

The South Australian Medical Treatment and Palliative Care Bill has now actually got out of its deadlock through a conference of both Houses in the South Australian parliament. That is a problem that you will not have. It has been passed. It contains a clause about the care of dying people, which talks about not intervening in a preexisting chain of causation. It is referred to in Latin legal terms: novus actus interveniens, a new act intervening in the chain of causation of death.

I would say that, in the example I gave, I did not introduce a new factor in the cause of that patient's death. But it is quite possible that I affected the timing. If, after due legal deliberation and consultation, it was believed that I had practised socalled pharmacological oblivion a term which you may hear Roger Hunt refer to there is a dilemma in terms of crossing the fine line. That dilemma in a sense brings this whole issue to the boil and is the reason why you are sitting there and I am sitting here. It is a fine line. Anybody who pretends otherwise is just kidding themselves. I would still say that my intention is to relieve her symptoms. In order to be able to do what I do within the existing law in all jurisdictions of this country, that is the way I defend myself in front of a court. I may or may not succeed.

**Dr LIM**: Accepting all that, the passage of this bill would take away that grey area. It actually would safeguard your actions.

**Professor ASHBY**: Yes.

**Dr LIM**: Some patients suffer from terminal hypoxia or just choking to death which would probably be one of the worst types of dying I can possibly imagine. This bill will actually allow such patients a very comfortable way of dying. Marshall Perron might say to you that this is the sort of case which he is explicitly trying to help.

**Professor ASHBY**: Yes, and I accept that intention. However, it would not be fruitful for me to second guess the evidence that you will receive, far more articulately and appropriately put, by others who will be called before you. They will oppose that position very strongly and give you many reasons why that is not the case.

It seems clear to me that this legislation, if passed, would cover that eventuality and in a sense would regularise something that is already happening. That is if the interpretation and legal advice received is that it is cold comfort to say that the doctor in a double effect is protecting you in those actions, in those extreme cases where it could be argued that, in order to abolish the suffering by rendering somebody unconscious, you might as well say that is the same as administering a lethal injection.

The question could be asked: 'How do you know how many milligrams will make the person nice and sleepy and then they will naturally die, as opposed to the number of milligrams that will just stop the person breathing in a few minutes or half an hour or whatever, in which case you might have been said to have actively ended the life?' No doctor, I believe, could sit here in front of you and say: 'The answer is 50 milligrams of whatever drug for this outcome and 55 milligrams for that outcome'. That is not possible. But you will receive a lot of evidence to say that, if you want to legislate for those hard cases at the end of life, we can understand you wanting to do that. However, hard cases make bad law. Look at all the other consequences of putting in a law like that.

There is a precedent here that is well accepted virtually everywhere in the palliative care world. It had a very powerful impact on your colleagues from the ACT when they were looking at Mike Moore's bill. I invited them to a team meeting at the Mary Potter Hospice. They agreed, of course, to observe confidentiality and so forth, and just sat in on the team meeting.

One of the patients had a large mass in the neck which we thought might erode the carotid artery causing the patient would haemorrhage to death an horrendous scenario. Going back 20 or 30 years, patients who are at risk of this complication, who are being looked after properly in cancer hospitals and head and neck units, would have a dose of morphine written up which is called a haemorrhage order. That haemorrhage order is clearly a lethal dose of morphine. If the patient is on 510 milligrams 4 hourly then this would often be for 20, 30, 40, or 50 milligrams. The idea was that, rather than let the person drown and haemorrhage to death, you would actually very quickly put them to sleep. That has been accepted practice. I am sure that, as I said before, the opponents of the bill before your Assembly would say: 'For heaven's sake, do not legislate on those hard cases. However, they are food for thought'. That has been accepted practice.

No doubt you have talked to that committee or received its evidence. The interesting implication for that committee was that, knowing that that could be done safely as part of existing practice and under existing law, presumably in South Australia and elsewhere, there was less drive and imperative to pass the Voluntary and Natural Death Bill that was proposed by Michael Moore in the ACT Assembly.

**Mr STIRLING**: Nevertheless, that does not solve the Rodriguez case.

**Professor ASHBY**: Quite right.

---

**Mr STIRLING**: There is always an exception. In terms of the bill itself, do you want to comment on any specific clause or on any weaknesses, deficiencies or dangers that you perceive?

**Professor ASHBY**: First of all, I just want to make a comment on the interpretation section. In part 1 clause 2, under the health care provider definition, I am not sure why you have lumped buildings and nurses together. No doubt the ANF will have already wondered why providers can be an institution or a nurse. I think you should clarify there that a nurse is a practitioner linked to a register. It might perhaps be better to define a nurse and give them the same recognition that you have given to medical practitioners. They are registered under the appropriate legislation in your Territory and no doubt they will be making separate submissions to you about the role of nurses in any proposed legislative changes. That is a trivial point but when I read it, it was immediately apparent to me that apples and oranges were being dealt with under the same clause. You have a drafting issue to be looked at.

Clause 6 concerns conditions under which a medical practitioner may assist. These strike me as being as reasonably stringent as they could be. You will no doubt be comparing them to the conditions that are imposed in Holland under the guidelines which have now of course been voted on by their parliament and adopted. It would certainly be interesting to compare them to the conditions set out by the Chief Justice of British Columbia and the Chief Justice in the Supreme Court of Canada. I think that they are roughly the same and in a sense, I think they show you just how hard this is going to be.

I know that Marshall Perron has been quoted in the press as saying that, if his bill was passed by the Assembly, few people would avail themselves of it. Presumably, his liberal democratic view is that they ought to be able to do so, even if the procedures that he has to draft in his bill are cumbersome and intrusive of privacy, as they are.

The idea of introducing a second medical practitioner into a home of a dying person for the sake of fulfilling the law is something that could on occasions be quite intrusive, disruptive and difficult for the patient and family. However, I am sure that it is essential to ensure that the clinical facts are as put to the patient and as quoted in the medical record.

In paragraphs (c) and (d), you have made the activating illness one that will end the patient's life in approximately 12 months. This is very difficult to determine. I appreciate that in drafting of law, you have to provide a number and be categorical rather than vague. You have left it open as to whether it is severe pain, suffering or distress. I assume that this could include mental distress, which makes it fairly wide, but still has to be in the framework of an incurable illness that will kill the patient within 12 months.

**Mr POOLE**: There has been some debate about 'distress' and whether it could be removed from it or not.

**Professor ASHBY**: If you look at the people who are reported to have received assistance in death, I am sure that there would be those, particularly in voluntary euthanasia

---

societies, who very much want to retain that breadth. When you really look at the number of cancer patients in 'excruciating terminal agony' who would be requesting assistance under the provisions of this bill, I suspect that it would be really quite small. There are, however, a number of people in Sue Rodriguez' position who no doubt would wish to avail themselves of it. It may well not be pain as such but loss of function that motivates them to make that request.

**Mr STIRLING**: Which is suffering and distress.

**Professor ASHBY**: That is right.

**Mr STIRLING**: In that Rodriguez case, it would be difficult to determine that 12 month period, I suppose. In those situations, there would be the dilemma of both remaining competent to make a decision under the bill and to be within the 12 month period in the opinion of a doctor.

**Professor ASHBY**: Yes. Within the reasonable body of medical evidence that is available on that particular topic, which would be substantial, the way you would probably address that would probably be to look at the rate of deterioration. With a recent case in which I was involved, I would have had no hesitation in a legal setting of saying that the overwhelming likelihood was that the person would die well within the 12 month period because of the rate of deterioration. At the end of the day, it is a clinical judgment. Like any other judgment, it could be wrong. I believe though, that in drafting the figure of 12 months, you have left yourselves open to assisting somebody like Sue Rodriguez.

I do not have any other comments about this bill which I received recently and have had an opportunity to read. Like many such documents, it is only many weeks later that you suddenly focus on something that you realise that you would like to reword. No doubt, in the process of your deliberations, aspects of it will become clear to you. In terms of meeting the objectives that it clearly sets out to meet, it seems to be a reasonable bill. To my mind, it does not contain any glaring errors from a palliative care physician's prospective, which is the prospective you asked me to present to you today. Obviously, you will receive other evidence on its legal implications.

**Dr LIM**: There have been suggestions that it might be open to abuse, that some general practitioners would go into collusion and start up an industry. Would you like to say anything about that?

**Professor ASHBY**: I do not believe that there is a danger of that. You would be talking about gross criminal activity. It is of course possible, but I think highly unlikely. I suppose it would not, in my view, necessarily be a reason for voting for or against this bill. You could argue that there are plenty of other statutes that 2 doctors could get together and fiddle, if they wished to, for some ghastly criminal motive.

**Mr POOLE**: Right. Is that everything?

---

**Dr LIM**: It would be an interesting question but I would not put it to you. It is just that you are asking us to abstain rather than to vote one way or another. I wonder how you would vote. That is all. But I do not think it would be fair to ask you that question.

**Professor ASHBY**: Well, I am happy to answer it and I do not think I should shrink from so doing. If I was sitting in your Assembly as a registered medical practitioner as you are, Dr Lim and as a palliative care physician, I think I would abstain on the basis that I actually do not think that this is the main issue with the care of dying people.

However, wearing my other hat as an MP representing a community where up to 8 out of 10 of my constituents say that they are in favour of this kind of measure and certainly if I was not a medical practitioner in that particular specialised area of medical care I think that I would probably vote in favour of it.

I would say that if it were voted in without adequate attention to palliative care, that would be a disgrace. As I have already indicated sufficiently, there is still quite a lot to do in this area of endeavour. I would say too that I think it is very important that palliative care services do not become known as euthanasia services. It needs to be absolutely clear to members of the public who very strongly oppose any move in this direction, that there is no way that they would in any way be coerced by any party into active assistance in dying. It would be quite a retrograde step if palliative care became the specialist service for active ending of life. There would be a lot of public mistrust of us if that were the case. I think it is important to keep clear about what we are doing and what our intentions are. I would have to say that I think that there are a lot of fears in the palliative care community of Australia that just that would happen if this were legalised in this Territory.

You obviously bear a very heavy responsibility in reporting this matter to the Assembly and the eyes of many other parts of Australia and the world will be upon you in your deliberations.

**Mr STIRLING**: Thank you very much. It has been most informative.

**Mr POOLE**: Yes. Thank you very much, Professor.

**Professor ASHBY**: I would just like to add that those last remarks are personal and do not represent the opinions of my professional body.

**Mr POOLE**: Yes, thank you.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 12.10 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr Roger Hunt, Medical Coordinator, Southern Community Hospice Program, Daw Park Hospice, SA

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

1

---

**Mr POOLE:** I declare open this hearing of the Select Committee on Euthanasia and welcome Dr Roger Hunt, Director of Palliative Care, Daw Park Hospice, South Australia, who is appearing as a witness to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful. I also advise that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses however do have the right to request that their evidence be taken in camera and/or remain confidential. Could you please advise if that is the case?

**Dr HUNT:** No. It is not.

**Mr POOLE:** Thank you. For the Hansard record, could I ask you to please state your full name and the capacity in which you appear today?

**Dr HUNT:** My name is Roger Wayne Hunt and I am a doctor who has been caring for terminally ill people. For the past 11 years, I have devoted my full time work to that. My current positions are: Medical Coordinator of the Southern Community Hospice Program and clinical lecturer at Flinders University of South Australia. I have been chairperson of the South Australian Association for Hospice and Palliative Care for 3 years. So my interest in terminal care has been longstanding. I see myself as an advocate for good terminal care for all patients.

**Mr POOLE:** Doctor, thank you for finding the time to appear. What we have been doing to date is inviting witnesses to either talk to a submission or make whatever comments they want to make. We then go into a general question and answer session, if that is agreeable to you. We have allowed a fair amount of time for you and will just play it by ear if that is all right.

**Dr HUNT:** Sure.

**Mr POOLE:** Over to you.

**Dr HUNT:** I guess this whole debate is happening in a society in which attitudes to this issue are changing quite rapidly. I included in my submission the Morgan Gallop poll results going back to 1962. A very straightforward question is asked about a patient who is in pain with absolutely no chance of recovering and who asks for a lethal dose so as not to wake again. Should a doctor be allowed to give a lethal dose or not? There has been a steady increase in the proportion of Australians who answer yes, that the doctor should be allowed to give the dose, and I would like to outline reasons for this.

I think people see it as a human rights issue in some respects. Attitudes have been changing because we have an aging population and old people tend to think more about death

and fear it less. We are having more and more deaths from cancer, whose terminal phase presents great challenges to health care professionals. There has been a growing disenchantment with medical efforts to keep people alive against their wishes. There are limitations on the ability of palliative care to relieve suffering and I would like to focus on that a bit more. The population is increasingly educated and assertive.

Often, 20 or 30 years ago, patients were not informed that they had a terminal diagnosis, so they were not aware of their options. They did not participate in the decision making. These days, we are hearing about informed consent and patients' rights. Many hospitals have patient advocates. Medical decision making has shifted from medical paternalism, with doctors determining what is right for you and what you are going to do, to patients wanting to have more say in what happens to them. Similarly, there is less traditional religious authority. In a more liberal society, there is a strong belief in the right to choose.

Palliative care has promoted the idea of passive euthanasia and autonomy, passive euthanasia being the withdrawal or withholding of life extending treatments if that is the wish of the patient. Palliative care has promoted the provision of comfort care rather than life prolonging care. It has promoted the idea of quality of life and of people choosing from a range of options for themselves. If anybody is going to judge the quality of life, it has to be the patient. So the patient is also in a position to judge what sort of treatment is likely to enhance their quality of life.

Those are some principles of palliative care that, I believe, are not in conflict with the principles of euthanasia. There are a range of options, focusing on the quality of life and what the patient wants. A lot of people portray this argument as one in which the euthanasia advocates are in one corner with the palliative care advocates in another. That is not the way I see it. I see that the basic principles advocated by both autonomy, options for treatment, focus on quality of life are similar.

In respect of the limitations of palliative care, I will focus on physical symptoms to begin with. This is an important topic because the palliative care community has traditionally said that all suffering can be controlled with good palliative care. I think that is a myth. In the past, it has been said that people who have good hospice and palliative care do not ask for euthanasia. That is another myth. They have also said that good palliative care would negate any need for euthanasia and the euthanasia movement only springs up when people do not have good palliative care. I think that is rubbish.

For example, in South Australia, where we had the rapid development of palliative care service to cover the whole state, there has been a parallel development of the euthanasia movement. The development of palliative care has not negated the euthanasia movement. In fact, both are growing together.

Perhaps it is worth exploring the history of the development of these myths in palliative care. I think the movement needed medical respectability and, in its beginnings, there was high idealism. The early leaders were Christian idealists rather than secular academics. As the

palliative care hospice movement has matured, it is looking at problems more objectively rather than in an idealistic spirit. For example, we are looking more at surveys of symptoms that patients experience. We are looking at how effective our interventions are with more systematic scientific methods.

Page 3 of my submission refers to a survey about the prevalence and severity of symptoms experienced by 100 cancer patients and the extent to which treatment helped, as reported by relatives. You can see there the very common symptoms of cancer patients. Weakness is experienced in 87% of cases. Of those 87% of cases, 75% involved severe weakness. Did the treatment help? Can you palliate weakness? 3% of the relatives said that treatment helped in severe cases.

Palliative care cannot remove weakness. Weakness is a symptom that can lead to dependence on other people, and independent personalities can find that very difficult to cope with. It can result in someone being bed-bound, needing help to get out to the toilet and needing to be sponged in bed. Such things can lead to a sense of indignity, feelings of being a burden on other people and so forth. Weakness is a major common symptom that a lot of people have trouble dealing with. Palliative care cannot make people stronger. It cannot treat all symptoms and remove them. The same applies to loss of appetite or weight loss. They cannot be easily treated.

Pain is a symptom that you have no doubt heard a lot about in this select committee. As you can see, it can be better treated than virtually every other symptom. People in the palliative care community have tended to stress the importance of pain, which is reasonable in the sense that a lot of people fear pain as one of the biggest things. It is something that can be treated better than the other symptoms . I think this is a part of the palliative care movement trying to stress how important it is by saying: 'We can treat pain'.

Again, that does not apply in all cases. There are some cases of severe pain which can be extremely difficult to treat. For example, a tumour nibbling at a nerve can be impossible to treat in some cases without bombing the patient out completely. The side effects of medication can put a patient into a state of pharmacological oblivion. In some severe cases of pain, that is the only way it is possible to get on top of it.

There is a range of other symptoms that we can treat with variable success. With something like confusion in terminally ill patients, again the only way of really palliating it is to bomb someone out, to put them into that state of pharmacological oblivion if there is no reversible cause that can be tackled. Those are the physical symptoms.

Then there are the psychological, existential, emotional and social problems to which counselling can be applied. How successful we are at treating these problems is difficult to say. There is not a lot of good research to show that social work intervention or psychiatric intervention or other interventions are good at relieving other types of distress associated with terminal illness. We are not really sure how well we are doing. The hospice and palliative care movement has tended to say: 'We address all problems.' All problems can be addressed but are they addressed to the extent of relieving people's suffering and distress?

---

At our hospice, we looked at the incidence of requests for speeding up the terminal phase. This is where state of the art palliative care is being delivered, a teaching unit of the Flinders University of South Australia. We have one of the world's first professors in palliative care, Ian Maddocks, who is the director of the unit. We have a high nursing staff ratio, a lot higher than in the usual wards. We have social workers, physiotherapists, pastoral carers and dedicated doctors and nurses a whole team of palliative care workers dedicated to the care of patients in the hospice.

At our weekly audit meetings, we asked the question: 'Did the patient who died ask for things be speeded up?' We found that 77% of patients never mentioned anything. 11% of patients made a comment to the effect: 'I wish it would hurry up'. 6% asked a staff member: 'Could you hurry it up?' Finally, 6% were consistently and persistently saying: 'Please, can you do something now to speed up this terminal phase in my life'. That 6% are people who would be candidates for euthanasia'. We are not talking about a high proportion of people who are dying. We are talking about 5% to 10%. In the Netherlands, of all cancer patients who die, 7% have euthanasia. That is not very different to the 6% who are asking for euthanasia in the hospice.

Most people can be kept satisfied and comfortable enough with palliative care but there are some people who are not. This is what this whole euthanasia debate is about. What do we do with those people who are dying and who are suffering and who ask for help to die? I do not think that we can simply turn our backs on them. I think we have to listen to them as closely as we can, find out what is underlying their request and see if we can do anything to help ease their suffering. We cannot just walk away from them. In some cases, after a process of negotiation and consultation, I believe that the patient and the doctor should have the right to negotiate voluntary euthanasia.

Perhaps I will leave my statement there and ask whether you have any questions.

**Dr LIM:** I think your use of the Morgan Gallup Poll was quite interesting. I sometimes have great difficulties with polling. Looking at the years from 1962 to 1993, I do not know about the population surveyed. We could look at baby boomers as being the great majority of the population surveyed. If you look at the period 1978 to 1993, there is a marginal rise. They are surveying the same group of people. I tend to disregard it because of that. Each year, they could select a very significant group of people, such as 18yearolds this year, 28yearolds next year and 38yearolds after that, so they do not get the same group of people each time ...

**Dr HUNT:** You are raising a question about methodology of the survey. The Morgan Gallop people are very professional in the way they do this. They do have these results stratified by age groups, from 18 to 30yearolds 30 to 40yearolds and so forth. They are stratified by age groups so you can see what different age groups think. I think that their sample number is over 1000 Australians. It is not a small group. They also stratify by political preference and religion. It is interesting that even people who say they are Roman Catholics are 70% in favour of euthanasia.

---

This is an interesting topic. As people move up the power hierarchy of organisations, they seem to become more conservative on this issue. As you get down to the grass roots, ordinary people such as ordinary Roman Catholics will say: 'Yes, I think people should have the right to have a dose if they are suffering and terminally ill'. As you go up the hierarchy of the church and get to the Pope, of course, it is a different matter.

I think a similar thing is happening in the medical profession. In the AMA, a leader such as Brendan Nelson is an example. He says that as a general practitioner he helped people to die. In fact he has virtually said that he has euthanased some of his patients. However, he is taking a conservative line as far as changing the law goes. It is a fascinating thing. Politicians have also tended to take a conservative side on this issue despite what people are saying that they want.

To return to your question, I have seen the sampling groups. Your point about the baby boomers is appropriate because they are a part of the aging society and they have always carried political power, from the time in their youth when they were able to stop the Vietnam War. Now that they are in their economically productive years, the economy is at the top of their agenda. As that population moves into old age, these issues are going to become all the more prominent. They have always wanted to say what is right for them.

**Dr LIM:** One of the other statements you made was about pharmacological oblivion. How often has that happened, if I may ask?

**Dr HUNT:** It is something we want to look into at Daw House Hospice, where I work. It is quite common, in the final days of life, as various organs are failing, for the patient to become confused and restless. For example, if a patient becomes hypoxic, low on oxygen, it can cause restlessness and agitation. When a patient appears distressed like that, it is distressing for the family as well. So we negotiate as much as we can with the patient and also with the family. Usually, it is a little butterfly needle under the skin attached to a syringe into which we put painkillers if they have been having a need for painkillers and a sedative called midazolam, which is a short acting benzodiazepine. It is given under the skin as a constant infusion to make the patient more peaceful and relaxed. Everybody feels more comfortable that the patient is free of distress. The proportion of dying patients who receive that treatment is about 1 in 3. It could be higher.

Some people have said that palliative care neither hastens dying nor prolongs life. I think it does both. For example, if you are giving someone good pain control, they can get out of bed and move around. They are not going to get static pneumonia from lying in bed all the time. However, giving treatment in high doses for pain, or sedatives towards the end of life, can render the patient virtually asleep all the time, unable to eat and drink. That type of treatment will predispose the patient to dying more quickly. Palliative care does both. It can hasten demise as well as prolong life, depending on the situation. I think we need to take responsibility for that in palliative care. If we are starting a treatment that could have the effect of hastening a patient's demise, the patient and the family ought to have that discussed with them.

---

**Mr POOLE:** You use percentage figures, such as 80% of Australians thinking that euthanasia should be available for terminally ill people who are suffering and request help to die. But could it not be said that many such surveys in Australia are answered fairly nonchalantly by the general populace? It is a bit like the capital punishment debate. Everyone would immediately say: 'Oh yes, I support it'. Yet we do not have capital punishment in Australia. We used to have a law , of course, but it was put to bed quite a few years ago.

**Dr HUNT:** I think this is a little bit different because people think about this in terms of themselves: 'If it was me'. In the case of capital punishment, however, they are thinking of what should be done to some other person who has committed a heinous crime. When asked this question, I think people tend to reflect on themselves or an experience which they have encountered, perhaps a parent or grandparent. I do not think that everyone is just answering nonchalantly.

**Mr POOLE:** Nonchalantly is probably the wrong word because, in what we have seen so far, it comes down to a debate about the sanctity of human life and the individual's right to choose. It just depends on who you speak to as to which side of the fence they are on. There is that moral question, I guess. I must say that I personally agree with you in relation to the preposterous idea that there is a hoard of doctors waiting around the corner just itching for this bill to come in so they can go and ...

**Dr HUNT:** That is a scare-mongering idea.

**Mr POOLE:** The same applies to likening it to the Holocaust and so forth. A lot of people do that, for whatever reason. Some are obviously genuine in their thoughts. It is interesting that you point out that Dutch doctors are now highly trusted and respected. I do not really understand the emphasis that our society has put on the various reports from Holland. If it is such a terrible thing, why have the Dutch people not risen up and said: 'Stop the killing!' Do you have any comment on that?

**Dr HUNT:** I have been to the Netherlands and I have spoken to some of the doctors who have led the way on this issue Peter Admirale, Dr Smook and a few others. They struck me as being very sensible men. The wife of one of the doctors told me that she can always tell if euthanasia is being considered with a patient. She can tell that he is thinking about it and is burdened with the responsibility. She said that, if he is removing breasts as a surgical oncologist, or doing other things like that, he does not worry so much.

Something similar probably also came through in the documentary about the patient with motor neurone disease. Doctors will not go into this willynilly. People recognise that it is a huge responsibility and we have to acknowledge that some doctors will never want to take on that responsibility. That is fair enough. It is their right and option. The ones that do it will not do it willynilly. If they are doing it sensibly, they will be very well respected by the families and of course the patients. That was the impression I got in the Netherlands, talking to the doctors there.

**Mr POOLE:** We have a peculiar problem in the Territory and I guess you probably would have the same problem if a bill such as this existed in South Australia. A fair proportion of our people in the Territory are Aboriginal people. Some would say that they have almost an inherent distrust of going to hospital. I am talking about rural Aboriginal people rather than urban Aboriginal people. They see that people leave in a plane to go to hospital and just do not come back. The distrust develops because it is so different to their way of life.

People have told us that they prefer terminally ill patients to be brought back to the community to die on their land because the land knows they are dying and they have various rites to be performed. I am sure that all members of the committee share my personal concern that we should not end up with a huge distrust of the medical profession so that people will not go to hospital and have a needle for measles inoculation because they do not really know what the hell was happening.

**Dr HUNT:** That is a problem of communication rather than a problem with euthanasia. Some people will play on those sorts of fears, which I think is a terrible thing to be doing. I am thinking about some of the right to life campaigners who, as I say, use scaremongering tactics on this issue. The message that has to be put across is very simple. It is that, if you want to live, euthanasia is not for you and nobody will give you euthanasia even though you might be terminally ill. I think it is important, for the best of terminal care, that these people do die among their families in their own environment as much as possible. I think it would be a tragedy if they are being removed from their own environment, put into hospitals and being isolated from their people at this important time.

**Mr STIRLING:** We have had evidence from Aboriginal communities themselves that the concept of euthanasia is well understood and, in fact, practised among themselves.

**Dr HUNT:** In what way?

**Mr STIRLING:** When an old person knows that they are dying, and the land knows, they make a decision in consultation with the family to stop eating and drinking. That is respected by the family and then the ceremonies and the preparations for death take place.

It is not a problem with the concept. What I think we got from them was: 'We know about this. We look after these sorts of things ourselves. We do not want you or the hospital having this sort of right because the message that will eventually go back is that doctors can now kill'. That is very unfortunate but it is the simple message that will get around the bush telegraph. Whether the bill is enacted or not, there will have to be a massive input into education as to exactly what has occurred or has not occurred.

**Dr HUNT:** Yes. Something springs to mind when you use that phrase: 'Doctors can now kill'. I guess the Aboriginal community has got used to the idea that doctors can stab people with knives as well, as they do in surgery. Doctors have taken on responsibilities that cut across some human sensibilities. The point I am trying to make is that there is a conditioning process where people do get used to ideas. I cannot be sure what the Aboriginal community would think of doctors doing surgery, whether there are problems with that. If there are problems with it, I do not think that it is necessarily a good argument for stopping surgery. It is an argument for good communication and trying to develop good relationships.

**Mr STIRLING:** I am interested in the point you make about trust in the doctor-patient relationship. I have no doubt that, by and large, Australians place enormous trust and confidence in their doctors. You say that there is a risk of that being undermined if the doctor is not able to listen and to accede to the patient's request if they want to die in the latter stages of terminal illness. Many people have come before the committee with the totally opposite view that, if this is allowed, the trust in the patient-doctor relationship is much more undermined. I guess you are coming from opposite sides of the fence and saying the same thing.

**Dr HUNT:** Yes. A lot of people are afraid that they are not going to be able to get help and there is fear on that side. There is fear on the other side that people will be killed against their wishes.

**Mr STIRLING:** It is not just that. A doctor suggested that the patient might come in with that thought uppermost in their mind: 'Does this doctor support euthanasia or not?' According to whatever the patient's views might be, questions like 'How are you?' or 'How is the family?' can appear to be loaded in the context of legislation on the books.

**Dr HUNT:** I think there needs to be open communication about this between the doctor and the patient. Currently, there are impediments to that sort of open communication.

In the Netherlands situation, people gave me the impression that doctors were very highly trusted and that patients would stick with the one doctor over a long period of time. There was a long standing doctorpatient relationship. You wondered why this is happening in the Netherlands. Going back to the Second World War, during the Nazi occupation, efforts were made to coerce the Dutch doctors into wrongful killing. The Dutch doctors resisted. Some of them were sent to concentration camps because of it. I think that was part of the motivation. Doctors were not willing for outsiders to tell them what they should be doing with their patients. They have a high level of trust and some of the reasons are historical.

**Dr LIM:** Let me pursue the question that Syd raised about trust in doctors. We all assume that doctors are of reasonable competence and ethical standards.

**Mr POOLE:** You are talking about doctors, are you, not politicians?

**Dr LIM:** But there are also doctors who have been prosecuted for maybe fraud, intercourse with patients in the consulting rooms and so on. There is an element among medical practitioners who are really not trustworthy. How do we control them if euthanasia is legal?

**Dr HUNT:** How do we control them now when euthanasia is not legal?

**Dr LIM:** That is not relevant. Whether you control it now or later, makes no difference. You still will not be able to control them. So how do you control them or do we just ignore that section of the medical fraternity, if you can call it a fraternity?

**Dr HUNT:** That is a difficult question. As you say, doctors are human and they will make mistakes. Some will be bad apples, full stop. The argument that you are putting is that we should not give doctors added responsibilities if they are not perfect.

**Dr LIM:** If we cannot control them.

**Dr HUNT:** I guess what is happening now is that euthanasia is taking place but is being pushed underground because of the way the law is. It is a doctor doing things in secret basically. I do not know that that is the best way to have things regulated. I think a better way is open discussion and research. Find out what is happening. Develop professional guidelines. Keep the law in there. If a doctor has been shown to do something wrong, or to be engaged in misconduct of any kind, he should have a writ or a malpractice claim slapped on him. But to have it pushed under covers in secret, is not the best way for surveillance and regulation. The best way is to have it open so that the practice can be properly scrutinised.

**Mr POOLE:** We put that question to another doctor and he came straight back at me and said: 'Well, look at domestic violence. It occurs in the home and usually you find out about it when somebody either falls out the door into the arms of the police or runs to the hospital'. The way to fix that, of course, is not to legalise domestic violence.

**Dr HUNT:** Domestic violence is an act against somebody's will. It is a different type of act. It is more like rape. Euthanasia, however, has as much to do with murder as making love has got to do with rape. Consent is involved. Having open discussion about domestic violence, which is what has happened in society over the past 5 years and by people seeing what is appropriate and what is not appropriate behaviour, you are going to eliminate the inappropriate behaviour. I think that is slowly happening with domestic violence. We are hearing more about it and it is more in the open. That does not necessarily mean that it is on the increase. It just means that people are talking about it more. That does not mean they are condoning it. It means that people are sort of getting it under control, in perspective.

**Mr POOLE:** One of the problems with this particular subject is simply the fact that we are talking about death. We do not talk about it a lot, although I suppose we do as we get older.

**Dr HUNT:** We think more about it, sure.

**Mr POOLE:** When you are young, everything revolves around life. Many changes have occurred over the years. I mean, doctors lied to patients about terminal illness 20 years ago. It is quite a marked turnaround.

---

**Dr HUNT:** Yes, it is. I do not think we are any longer a death-denying society. Certainly in the 1950s, the 1960s and probably the 1970s, we tended to be a death-denying society. That has changed. The taboo has gone and, although death seems to be sensationalised in the media ...

**Mr POOLE:** I believe that it has changed because of the media. Most people, 30 or 40 years ago, could go through their whole lives without ever seeing a dead person unless it was their own parents at a family funeral, depending on their religion. Now you see death almost nightly on the television. All those attitudes have changed, I think.

**Dr HUNT:** Deaths on television, however, tend to be unusual and violent deaths. You do not see the usual sorts of deaths, cancer being the leading cause of mortality in our society. You do not see much about people dying of cancer on the television news. It is all about dramatic things.

Back in the old days 100 years ago, when the extended family was more evident and people lived in rural settings more, they were much more in touch with the life cycle. Death was part of everyday life. But as we became more involved with hospitals, death was taken out of the community and the home setting and put into the professional domain, in hospitals, where it was not dealt with well.

In large part, the hospice palliative care movement was a reaction to that because dying patients in hospital were treated as if they would get better or were neglected in favour of patients who were getting better. Families were kept out. Visiting hours were between 3 and 5 and, if you were in the ward, the hospital's routines took precedence over more human concerns. That has turned around now. I think our attitudes have really softened. We are more caring as professionals, more focused on the needs and interests of our patients rather than just having our own paternalistic agenda. We are more mature as a society. As a society and as a community, I think we have come to the point at which we can handle something like euthanasia.

**Mr STIRLING:** Doctor, there is something of a paradox here. We have had palliative care people before us who have not been in favour of euthanasia. We have also heard from pro-euthanasia people who are strongly in favour of palliation. There is a distinct difference in your case a palliative care doctor putting the case for euthanasia. One witness put to us strongly that, if it were enacted, the practice of euthanasia ought to be kept altogether separate from that of palliative care. Correct me if I am wrong, but you seem to blur that a bit in the paper, suggesting that they can exist together.

**Dr HUNT:** I think they can. I think patients should have access to the best of care, the best of terminal care, the best of palliative care. But, if anybody is in a position to judge whether a patient is reasonable in asking for euthanasia, I think it would be someone from palliative care. If there are other techniques for controlling the pain or if the patient is unusually depressed for a dying patient, the person who is experienced in terminal care should be able to judge that sort of thing.

---

I really think the palliative care doctor is in a good position to judge whether euthanasia is appropriate, and I think euthanasia will eventually become part of the palliative care repertoire of treatments. My prediction is that it will be the last resort measure to relieve suffering at the patient's request. It fits in with the ideals and principles of palliative care that the palliative care community has so far traditionally rejected the idea. I think the rejection of euthanasia by the palliative care community is softening. As evidence of that, a policy was produced just this month by the Australian Association of Hospice and Palliative Care. I do not know whether anybody else has spoken to you about this but ...

**Mr STIRLING:** It is still a draft, is it?

**Dr HUNT:** No, not now. There was a media release on 7 April from the Australian Association of Hospice and Palliative Care. It is basically not different to the draft but it is one of the most progressive statements from a palliative care community that I have come across. Most other palliative care organisations say: 'We are strongly opposed to any move to the legalisation of euthanasia'.

That is going to change over time. I have no doubt about that. The first evidence of that change is this document where people are saying: 'Sure, the legalisation of euthanasia is not a substitute for the proper provision of palliative care'. But they are also saying: 'We cannot keep everybody comfortable all the time'. That is a big admission from the palliative care community. It believes that some patients rationally request euthanasia another big admission. There is less idealism, less rhetoric and more reality and honesty coming from the palliative care community now. As we go into the future, I think that will happen more and more.

Eventually, I think people will see that the concept and the proper practice of euthanasia is not far removed from palliative care. In fact, it is within the same ambit of good terminal care. I believe that will eventually happen and that we are now seeing evidence that we are headed in that direction.

**Mr STIRLING:** If there is a remarkable change going on within the world of palliative care itself, that change will also have to take place at some later point in the community. Most people in the community who are across the question to any extent would generally know that palliative care is there to see you right through to the end of your days and they are not going to kill you. With that change taking place there, it will also have to take place over time in the community.

**Dr HUNT:** In the way that palliative care is perceived.

**Mr STIRLING:** Yes, if euthanasia does become an end point or a last resort.

**Dr HUNT:** Palliative care and hospice care has an image problem in dealing with death in itself. We have broken the taboo but some people still will not like to go into the hospice because that is where people die. It depends on where the individual is at. In medicine

---

and in palliative care, we should be seeking to satisfy the needs and interests of each unique individual as best as we can. By having the sweeping rules that currently apply, patients do not have the full range of options that they are asking for and you are not giving doctors discretionary powers to negotiate with the patient about the best way to satisfy their needs and interests. There are restrictions that I think should be loosened up.

**Dr LIM:** You obviously believe that the personal choice is more important than the social common good, or the greater good of society that life should be sacrosanct?

**Dr HUNT:** There are a couple of different levels of argument here, I guess. One is that the wishes of the minority group, this 5% of dying people, should be sacrificed in the interests of the broader community. I am not sure that anybody has established that, if you are satisfying the wishes and interests of that minority group, you are going to have a detrimental impact on the rest of the community. A lot of fears have been promoted by the Right to Life organisation but I do not know that they have actually demonstrated a clear link there.

Then there is the moral issue about the sanctity of life, the more religious question that only God gives life and only God should take that life away. We all have different belief systems and different sets of moral values. In a pluralistic society, we acknowledge that. So, in this society, it is not appropriate to impose one set of beliefs on every member of society.

With the issue of capital punishment, the justification for breaking the sanctity of life principle would be as a deterrent or as retribution. With self defence, it is protecting your own life against somebody else. With euthanasia, we are talking about something that the patient is wanting for themselves. The justification is compassion and the desire to relieve somebody of their suffering in a way that they choose. If there is any justification for breaking the sanctity of life principle, I think the justification for euthanasia is certainly better than capital punishment, in which case you break it for retribution and as a deterrent.

I think it is possible to justify euthanasia on moral grounds in terms of a pluralistic society and the egalitarian principle, trying to meet every individual's wishes and interests to the best of your ability. I think that is the important principle that we should go by in medicine: do the best for each of our patients.

**Dr LIM:** In response to something Syd asked you earlier, you responded by saying that euthanasia is part of a continuum of treating the patient in a holistic sense.

**Dr HUNT:** Yes.

**Dr LIM:** Would patients then ask how hard is this doctor going to work on me before giving me euthanasia as a choice, as one of my options? How hard would this doctor work on my life before he says: 'Look, I am sorry, I cannot do any more. This is the last option'?

**Dr HUNT:** Okay. If a doctor gets a request for euthanasia, the natural thing to do is to find out why the person is asking to die. Is the patient in pain, is the patient suffering in

other ways, is the patient depressed? What can I do to make this patient's life better? I think that will be the natural thinking of any doctor. I have tried to stress that doctors will see euthanasia as a last resort. They are not going to be jumping in. It is an extremely difficult thing to do and some doctors will never want to practice euthanasia at all.

In answer to your question, I think patients will see that doctors will redouble their efforts of palliative care. They are not going to suddenly just say that it is over. If a doctor does that without consultation with the family, without proper negotiation with the patient over a period of time, that will be a dangerous thing. I suspect that that doctor would end up in trouble sooner or later through malpractice, negligence or whatever. It would be poor practice.

That is one reason why the profession itself needs to get its act together, because it is happening. Surveys show that it is happening out there but there are no professional guidelines indicating, say, that 2 doctors should be involved, that there should be specialist consultation if there is any doubt about pain or psychiatric problems, and a period of negotiation involving family if possible. Those sorts of professional guidelines need to be clearly put out so that doctors understand exactly what they need to be doing.

**Dr LIM:** At present, those regulations are not in the bill. Would you suggest then, that if the bill were passed, perhaps there should be a 6 or 12 month moratorium while doctors get up to speed on palliative care, counselling techniques and so on, before they are actually allowed to practise the act of euthanasia. In the example you gave about the patient asking for this as a last option, you were talking about a palliative care expert who is pretty well up to speed on that. Now, there are lots of doctors like myself who are not up to speed. Where do you go from there? If the law is in place, I can perform the act from the first day. Would you suggest a moratorium of 12 months?

**Dr HUNT:** It is something I had not considered but I think it is a good idea. I think naturally doctors are not going to suddenly be doing something they do not feel confident with. They would feel their way slowly.

**Dr LIM:** Are you saying they should learn by their mistakes?

**Dr HUNT:** Yes, there could be mistakes along the way. I think the idea of a safety period is sound. There could be intensive education on palliative care, and some education on techniques of euthanasia. You might even get some experts from the Netherlands who have been involved in situations there. Certainly, education on palliative care and terminal care, the principles of the act and what would be necessary, would be a tremendous idea.

**Mr POOLE:** Doctor, one of the things that came to light through talking to other witnesses and amongst ourselves is this period from the time the patient requests their ability to undergo euthanasia, and when it is actually carried out. Whilst the terminal illness time is 12 months, one would presume that you are not going to have a situation whereby a certificate is issued and the actual injection immediately takes place. Another grey area of the bill is that

it does not say exactly how the act is to be performed. It seems a little bit illogical that you would allow people to go through the next 6 months or whatever with a certificate in their back pocket virtually ...

**Dr HUNT:** Yes, people will want reassurance that, when their quality of life diminishes to a certain point that they say is intolerable, they will receive help. The negotiation will start well ahead of time and ...

**Mr POOLE:** I mean, I can understand the case of an aged patient who might, in theory, sit on it for a couple of years and depending on what symptoms they had ...

**Dr HUNT:** Absolutely.

**Mr POOLE**: ... whereas, in a terminal cancer patient, it might only be a matter of weeks, days or whatever. It just seems a little incongruous that, on the one hand, we have a 12 month period in which the doctor is saying that you will be dead whilst, on the other hand, we are allowing people to make a decision, and possibly get to a stage whereby they become mentally incompetent and are disqualified because of that.

**Dr HUNT:** I think there needs to be some sort of advance directive where the patient can say either: 'Let me give you the word when I have had enough' or 'If I become incompetent, incontinent or confused, and there is no way it can be reversed, that is when I want out'. If the doctor and the patient could negotiate some sort of advance directive like that for the timing of the euthanasia ...

**Mr POOLE:** Rather like the living will situation?

**Dr HUNT:** Yes, for the timing of it. It is a contract between the doctor and the patient.

**Mr POOLE:** The difficulty under the terms of this bill, of course, is that once you get to that stage, if you are not judged to be competent even though you might have had the bit of paper signed 6 months before, technically ...

**Dr HUNT:** If you are not competent at the time. That is a difficulty with the bill, I think. If somebody is terminally ill and is dying, they may be confused at the end. That is what a lot of people fear. They do not want to be a vegetable at the end or distressed because they are completely muddled for one reason or another.

**Mr POOLE:** Logically, I can see that if it was me and I was in favour of the bill and said to you that I had AIDS or whatever and wanted you to terminate my life, I would fill in all the forms. But I could not see myself doing it until I got to the stage that the illness was really making me uncomfortable and I was suffering pain. Presumably, if I was not, I would not qualify under the terms of the bill because it says pain, suffering and distress.

15

---

**Dr HUNT:** Yes. There was an interesting case of a lady in Canada with motor neurone disease. That is where all the muscles get weaker and weaker and weaker. I do not know whether you have heard of it.

**Mr POOLE:** Yes, we were discussing it this morning.

**Dr HUNT:** She said: 'I do not want it yet. I want it when I am completely paralysed and cannot do anything in my own life. That is when I will need help'. On the basis of discrimination, she was arguing that she should be able to get that help.

**Mr POOLE:** Yes.

**Dr LIM:** I do not quite follow what you say on page 5 of your submission. You say: 'It seems to me the principle of double effect is a psychological construct or a psychological defence mechanism which enables clinicians to intervene in suffering, with life supporting actions, while appearing to defend the sanctity of life principle'. Can you go into a bit more detail? I just do not quite follow the argument.

**Dr HUNT:** I was thinking of a situation where we are giving large doses of opioids and sedatives which could hasten the death of a patient. I will give you a case as an example.

I was treating a prominent politician in South Australia who had motor neurone disease. He was on a ventilator and virtually could not move anything. We had had numerous discussions. He was a great believer in euthanasia and felt that he should be able to carry a little white pill. He had not thought about it much until he was actually in the situation. He had only just retired from parliament.

He got to the point where his quality of life had diminished. He was not sleeping. He was afraid he would choke. He was getting low on oxygen. I started an infusion of sedative and opiate for him but it did not seem to help. I think it was just making him more hypoxic. I visited him when his wife and daughter were there. He could barely communicate at the time.

Consent is an issue there but he had given an advance directive, if you like. I disconnected him from the ventilator and gave him an injection of opioid and sedatives because he was restless, and he died. That all happened within the space of 90 minutes. It was removing a few aspects of treatment and giving palliative care to try and relieve his suffering. The effect of all that was that he died during my visit.

In some ways, it may have been kinder if I had given him a lethal injection. It really is an irony. In some situations, the kinder thing would make you a criminal. If I were to say that, by removing him from the ventilator and giving him the injections, my intention was to hasten his dying, I would be a criminal. I would be breaking the sanctity of life principle.

A lot of clinicians cling to this notion of: 'My intention is purely to relieve suffering, purely to remove futile treatments'. I do not think that intention is all that clear cut. I think

---

other intentions can come into play, not necessarily bad intentions. The automatic assumption of the law is that, if your intention is to shorten life, it is bad and you are a criminal. That is the automatic religious assumption as well.

That is where the problem lies because it (death) is a consequence of a treatment. The person who is removing the ventilator and giving that type of palliative care should realise that a consequence of their actions is that life is going to be shortened. If they are sticking to the principle of double effect and the principle of law, that person will not admit that intention. They should be aware of the consequences but they do not want to take responsibility for it either in law or in religious principle. I think it is bad medicine when responsibility is not taken for the side effects of treatment. The doctor needs to be aware of the side effects and to discuss them with the patient and the family. The way things are at the moment, it is biasing practice to be dishonest.

Some people are going to need to operate within that framework because of their own belief systems. In believing that they should not interfere with the timing of death, they would see it as death from natural causes without them having any impact on the timing of death. To me, that is a fanciful way of thinking. I think that person is impacting on the timing of the death and ought to be taking responsibility for it.

That is what I mean when I say the principle of double effect is the sort of psychological construct which enables people to intervene in suffering whilst believing that they are still upholding the sanctity of life principle.

**Mr STIRLING:** That just reminded me of a minister who said to me: 'This is dreadful because, in a situation of suicide, we allow there to be doubt. But in the case of euthanasia, of course, there can be no doubt'. I thought ...

**Dr HUNT:** Doubt about ...?

**Mr STIRLING:** That the person did want to die and in fact sought assistance to die.

**Dr HUNT:** Right.

**Mr STIRLING:** It may well be a very clear case of suicide but they ignore it and allow that there was doubt that in fact it was suicide. Under euthanasia, there can be no doubt. Some churches have a problem in how to deal with that.

**Dr HUNT:** Intention is not always clear cut. I think a better basis for public policy is to show that what doctors are doing is with the consent and the wish of the patient. In my paper I say: 'Doctors are there to serve the wishes and the interests of their patients rather than patients being there for the good intentions of doctors'.

**Mr STIRLING:** Do you have any other concerns with the bill at all?

---

**Dr HUNT:** I have not gone through it with a fine toothcomb. The 12 months is a guideline and doctors do have some ability to judge whether a patient is likely to live days, weeks, months or a year. The principles are good, as is the idea of getting it out in the open, getting it regulated, acknowledging that it does happen and trying therefore to do it in a proper way.

The whole discussion is going to improve palliative care enormously, particularly if there is intensive education for doctors. Every doctor could be given a booklet on palliative care. There could be lectures and things like that happening. So there is a lot of good coming out of this whole debate. In the end, I think euthanasia could probably be introduced without controversy. It could be just happening very gently to a very small number of patients who want it and people will wonder what all the fuss was about, I suspect.

**Dr LIM:** What about the slippery slope argument, that has always been raised in relation to euthanasia?

**Dr HUNT:** I think there will be some sort of conditioning process. I remember the first time I went into the anatomy dissection room and saw a dead body and we had to sort of cut it up. It is a horrible thing but after a while, you focus on doing the right thing. The first time in an operating theatre, when the scalpel makes the surgical incision, it turns your stomach. It cuts across human sensibilities but after a while you get used to it and you focus on the job, the good thing you are trying to achieve. I think the same sort of thing applies with euthanasia. It does hit many doctors in the face. They think: 'This is wrong'. It cuts across those human sensibilities but when you are confronted and challenged by situations as I have been over the years I think you focus on your role and the right thing to do, what is right for the patient after knowing them very well and listening to what they want.

As far as the idea of the slippery slope is concerned, I think there is a conditioning process that happens but that is entirely ...

**Dr LIM:** A de-sensitisation?

**Dr HUNT:** Yes, if you like. It is entirely different, however, to the slippery slope argument which likens it to the Nazi Holocaust. To me, it is a bit like saying: 'If Australia becomes a republic, we will be on the slippery slope of nationalism and Australian forces will be in New Guinea and New Zealand before we know it'. It is that fanciful sort of fear-mongering argument and I think it is not a good one. It portrays doctors as being abusive. The role of doctors is to protect the vulnerable, weak and sick and dying as best we can, to protect their rights and interests, not to abuse them.

**Mr STIRLING:** There is a less emotive slippery slope argument, if you like. It does not descend to the Holocaust but it suggests that other groups will be drawn in, such as seriously deformed infants and quadriplegics who have lost quality of life. Your Rodriguez case in Canada is relevant. The suggestion is that there would be pressure, once this was enacted, for the definitions and the scope to be widened to take in other groups. In terms of

what the bill itself seeks to do, I would have thought that it would be entirely consistent that those other groups ought be considered. I am saying that this is an argument, without the emotion and rhetoric of the overall slippery slope viewpoint.

**Dr HUNT:** Yes, and I think there is some evidence from the Netherlands that other groups are beginning to be included. Whether that is a good or a bad thing is difficult to judge. I think this bill is a minimalist bill in saying that it has to be a competent patient and a competent ...

**Mr STIRLING:** ...a competent public.

**Dr HUNT:** Many people would fear ending up in a nursing home with Alzheimer's disease, completely off the air, incontinent and so on. They would not want that for themselves and would rather have a lethal injection and be out the way. This bill does nothing to address those sorts of problems. If this bill were to include a wider group of situations, it would be more open to criticism from certain quarters. I guess it is minimalised to see whether this minimal situation can be agreed to by the politicians. People may ask at later stages: 'What about this situation? Should I not have the right to euthanasia if this were to happen to me?' Those sorts of things could be considered at later stages, I guess.

**Dr LIM:** In another stage there is the possibility that the base will broaden. Is that what you are saying? That this is the first step in a long walk for humanity?

**Dr HUNT:** There are going to be other situations that present incredible challenges as well. This bill looks at a small group, a group of competent patients. If any bill can be passed on this issue, it would have to be with that group of competent patients. But there are other situations where euthanasia might be the right thing and there might be an expansion years down the track.

**Mr STIRLING:** This might be somewhat unfair. You come from South Australia and a bill is in the House there. What is the community feeling and what chance of success does it have in South Australia?

**Dr HUNT:** I get a feeling that the domino principle applies. It started here with the introduction of some legislation and South Australia and the ACT are also involved. It will be happening throughout the developed world. I think the developed world has reached a point of maturity now where it is looking at the rights of terminally ill people in this way.

I suspect that there will be failed bills in parliament and that, after a failed bill, another bill will be introduced at a later date. Eventually, bills will be passed, I think. If the current bill in South Australia fails, which I suspect it probably will, it will be followed up by another bill.

**Dr LIM:** A doctor raised the issue with us not so long ago about using the termination of pregnancy as an example. At 14 or 16 weeks of pregnancy, you can do blood tests and ultrasound scans to detect foetal abnormalities and in fact a midtrimester abortion can be carried out quite legally. Even at 20 weeks, you can still do the abortion. However, the opposite side of the question is that babies born 20 weeks prematurely are still salvageable.

---

**Dr HUNT:** Right, yes.

**Dr LIM:** On one hand you can abort and on the other hand you can save them. The dilemma comes along as to when you abort and kill at 20 weeks prematurely or you kill at 14 weeks of maturity. Really, it does not make much difference. If you have euthanasia at the end of life, what is the difference in having euthanasia at the beginning of life? Therein lies the slippery slope argument. Do you see that sort of thing now starting to increase as a first step?

**Dr HUNT:** We are talking about voluntary euthanasia here. It is different to abortion because, in abortion, the life being terminated has no say in it at all. When we are talking about voluntary euthanasia, the act is being done because of the request or demand of the person, who is terminally ill, has lived their life, is going to die shortly and is suffering. It is an entirely different situation. I know what you are asking: is it going to expand somehow? I am not sure that I can give a good prediction on that but the situations of abortion and euthanasia are different because of that principle of autonomy.

**Dr LIM:** Except that the question of autonomy in the abortion debate is about the woman ....

**Dr HUNT:** Yes, it is the rights of women versus ...

**Dr LIM:** ... rather than foetal autonomy. You are talking about the woman's autonomy now. The woman's autonomy says: 'I want to have an abortion'. Whether that is at 20 weeks or not is not the question. It is autonomy. Autonomy on euthanasia, at the other end of life, is still autonomy. I personally do not see the difference between those two autonomy arguments.

**Dr HUNT:** Both are autonomy but it is whether the autonomy belongs to the person whose life is being ended or not. In the case of the life of the foetus being ended, there is no expression from the foetus of whether it wants to live or die. In the euthanasia situation, however, it is only that person whose life is being ended who is able to say whether that is what they want.

**Dr LIM:** Thank you.

**Mr POOLE:** Are there any further questions? No? Thank you very much, doctor.

**Dr HUNT:** Thank you. I think you have a great opportunity here to come up with a good report and, hopefully, to be progressive.

**Mr POOLE:** We will try.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 14.25 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives: Australian Medical Association, NT Branch

Dr Chris Wake, President

Dr Diane Howard

Dr Phillip Carson

Dr Charles Kilburn

Prof. Norelle Lickiss

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** I call to order this hearing of the Select Committee on Euthanasia and welcome the following witnesses who are appearing to give evidence: Dr Chris Wake, Dr Diane Howard, Mr Phillip Carson, Dr Charles Kilburn and Prof. Norelle Lickiss.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to the committee should be truthful.

I also advise that the committee has authorised that, for the purposes of this inquiry, the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right, however, to request that their evidence be taken in camera and/or remain confidential. Please advise us if this is the case.

For the Hansard record, please state your name and the capacity in which you appear today. It is probably easier if you state that prior to speaking.

**Dr WAKE:** I was going to introduce each person, Mr Chairman.

**Mr POOLE:** Fine. We have been allowing witnesses to make their submission or speak to their submission before moving into a general questionandanswer session. We have allowed an hour, but if we need more time I guess we can find it. We will try to stick to the timetable if we can.

**Dr WAKE:** Absolutely.

**Mr POOLE:** Please allow us time to ask some questions.

**Dr WAKE:** Mr Chairman, the Northern Territory branch of the AMA is very grateful for the opportunity to come and speak to you today about some of our reservations in the matter of the Rights of the Terminally Ill Bill. We represent a properly constituted committee of the Northern Territory branch of the AMA. We are here as the representatives of the federal AMA The Chief Minister holds a letter to that effect. We are here with the full support of all other state and territory branches of the Australian Medical Association. I shall introduce our team.

Dr Phillip Carson is the senior specialist surgeon at the Royal Darwin Hospital. He has many years of experience in that field, and deals with palliative medicine cases.

Prof. Norelle Lickiss is internationally renowned in the field of palliative medicine. She runs the Central Sydney Palliative Care Service. This is a referral service. One might say that she fields the difficult cases. She has numerous publications to her credit. Interestingly, she knows most of the major players personally in this matter. She knows Prof. ...

**Mr POOLE:** We feel as though we do as well.

**Dr WAKE:** Names like Remmelink, Kuhse and Singer number among Norelle's friends.

---

I am the current president of the Northern Territory branch of the AMA. I have 15 years of experience in general practice in Darwin and a wide interest over those years in palliative care in the community. During the last 4 years, I have been running the casualty department at the Darwin Private Hospital and coordinating inpatient services to some extent within the hospital. I also am the primary care provider to the Northern Territory prison system in the Top End.

Dr Diane Howard is a senior specialist physician, both at the Royal Darwin Hospital and Darwin Private Hospital. She has been regularly involved in teaching and in palliative medicine within our community.

Dr Charles Kilburn, senior specialist paediatrician works in both Darwin Private Hospital and the Royal Darwin Hospital.

So we bring, sir, accumulated wisdom. We presented this submission, the green book which you will have. We commend the document to you. By virtue of the time involved, I would not say that it is a definitive statement, but we tried to cover most of the issues in a rational and even-handed fashion.

With your indulgence. Mr Chairman, we do not intend to speak to the document. We wish to present to you 3 cases which point up the various issues, and to discuss those with the committee. We would then like to go through the bill on almost a clausebyclause basis, to show you where we have major concerns. Then, by virtue of the fact that we have someone of the eminence of Prof. Lickiss here with us, we would like to make her available for a short questionandanswer session before I make a very brief summary. I hope we can do all that in an hour.

**Prof. LICKISS:** I am probably best described as a cancer medicine specialist and specialist physician since 1970. I am getting old. Since 1985, I have been fulltime in referral practice in palliative medicine. That is a little bit of a mixture.

I have a couple of cases to help tease out some of the issues. I know that there is a lot of confusion and I thought these might be helpful. These are actual cases, with very few words changed so that they cannot be identified.

The first was a professional man who developed a malignant condition which proved unresponsive over a few months to intense medical therapy. Although distressing confusion and some psychotic features were successfully treated, these bouts had distressed him and his wife. I can leave the text of these cases for you if you like. It might save some time. Hypercalcemia can disturb cognitive capacity dramatically with some psychotic features in a previously totally normal person. It is very distressing for a professional person, or any human being.

We were asked to see him. One of the things in the Royal Prince Alfred palliative care service is that one is constantly involved not only in trying to alleviate a situation, but also in

---

actually helping the decisionmaking. That is just part of the interface of a hospital, although some of my work is in the community and in nursing homes. We were asked what to do. He said to me that the biggest thing he wanted was space and time to get his resources together. He was just fed up with being in a very busy hospital. I should say that 2 3rds of about 1000 new patients we see each year are seen in the wards of Prince Alfred Hospital.

We decided to transfer him to a palliative care unit 3 kms away. While he was really cared for, he relapsed a bit and became very weak and deteriorated very rapidly. By the end of the week it was fairly clear that he was going to die. By the Friday, and the Saturday morning in particular, it was clear that there was something dramatic happening rapidly. His wife, who was a very intelligent woman, was very concerned that he was going into another bout of hypercalcaemia. She could hardly bear the thought.

Anyway, the question was what to do. I went to talk to him on the Saturday morning and he said he did not want to fight any more. He had had a lot of treatment in the last few months. I felt that it was right to tell him that the possibility was that we were just on the edge of an episode of hypercalcaemia. He reiterated that he did not want anything done about it. He actually said: 'I wonder about the needle, but I am only talking to you about that and I do not really mean it'.

What was very clear was that he did not want me to investigate, even if was hypercalcaemia. His wife was very distressed at this. The medical possibility remained that there were 2 conditions, hypercalcaemia or septicaemia, both of which were intrinsically treatable. This man did not want to be treated. So it really raised the question of what one does in those circumstances.

My particular ethic is that the patient's views, when they are clearly articulated, should prevail. Not everybody would agree. The wife was distressed and she had to be counselled and supported. She was, and it was agreed that no further tests be done. I explained that I was not prepared to deliberately accelerate his death and he really did not want that. What he wanted was to be allowed to die. We gave him a little bit of treatment, a few drugs.

On the Sunday morning, he became very emotionally distressed again. We were very much dealing with a man in the last days of his life. We added a small dose of sedation. I went to the hospital that Sunday afternoon to talk to him again, to see if there was anything I could do to comfort him. He did not know me. I think I knew in my own mind that he was dying of septicaemia, but that is not so much germane to the case. The issue was what should be done under such circumstances.

The case was one where, in fact, the patient's views were taken account of. We did use very modest doses of sedative drugs. They are not such doses that would knock anyone on the committee around. They helped him to feel calm, and he died a very peaceful death. I introduce that case because I think it does raise relevant issues. I think my colleagues want to comment on that case.

---

**Dr HOWARD:** Although this is an example of a man dying in Sydney, it could well be a local case. The issues and problems involved provide a good example of the sorts of problems that those of us involved with the care of very ill patients have to face several times a month. We chose this case to comment on because it demonstrates 2 main points about the care of patients who are dying.

The 1st point and this is really very important is that it demonstrates just what can be achieved with a good Natural Death Act. In fact, the Territory does have a good Natural Death Act. I think it is very sad that the public in general is unaware of the existence of that act. Those who are aware of it have no idea of their rights under the act and very few people have any idea at all of how they should implement those rights or express their wishes. I think this is something to which this committee should pay attention.

With the existence of a Natural Death Act, the patient has a right to declare their wishes as to how their death should be managed, has a right to specify what limitations should be placed on investigations and treatment. They negotiate this with the doctors and make their own viewpoints very clear. That is what this man did. He said, 'Enough is enough', and he defined that limit of investigation and treatment.

Secondly, a doctor working under the provisions of a Natural Death Act has a responsibility to work within the patient's guidelines. In this instance, the physician involved had lots of great ideas as to what might be causing the patient's unwellness on that particular day. There were investigations and tests which could have been done, and there were treatments she could have given. But the patient had said: 'Enough'. The doctor, knowing she was working with a truly terminal disorder and that the man only had days to live, was professionally and morally obliged to work within those guidelines. She did that, and that is how a good act works.

The third point about the Natural Death Act, as illustrated in this particular case, is that the doctor has the right not to follow the instructions of relatives if they are contrary to the expressed wishes of the dying person. Sometimes that can create very difficult situations, but experienced people will negotiate their way through that, at all times honouring the wishes of the dying patient.

The second aspect of this case is that it illustrates how good terminal care and comfort can be provided to assist the patient with the dying process not to kill them but to assist them with the process of dying. That is what we do all the time. It angers those of us who are involved in patient care to hear the advocates of euthanasia using the phrase 'assist the dying' as though they are the only ones who really help. We help all the time by comforting them and easing them through this very difficult time.

In this case, the treatment that was given was sedation in doses adequate to relieve distress, in the knowledge that this may reduce the level of consciousness or awareness of the patient and, indeed, even induce a sleep-like state. I would point out that this is not killing. This is not euthanasia. This is relieving a symptom. It is widely recognised as being an acceptable method of behaviour and it does not contravene any professional ethics.

---

In other situations, it may involve the use of a drug where the dose required to relieve a symptom is likely to result in an earlier death. Just to explain what I mean, I ought to give you another example here. A woman was dying with lung disease, caused by cancer which had spread to her lungs. She was talking about how she wished her dying to be managed and what contribution she felt I could make to make it easier for her. She said: 'I very definitely do not want to die feeling breathless, because I have had asthma all my life. I have always been frightened of dying breathless'. We talked about this particular point and I suggested to her that we should use morphine, which is not only a good drug for relieving pain but is a good drug for blocking the sensation of respiratory distress. With the use of morphine, she was able to face her death with confidence.

It is likely that, because morphine is a respiratory depressant, its use to relieve her distress may have caused her to die a few hours, or perhaps a day, earlier than she would have done without treatment. But the profession does not call that killing. It does not call that euthanasia. The primary aim of the treatment is to relieve the symptoms of the patient. It is not to kill the patient.

In summary, this 1st case illustrates that with a good Natural Death Act, patients are able to control the circumstances of their own dying, and physicians are able to offer comfort and care to assist them with the process.

**Prof. LICKISS:** Obviously, in the management of such a case, the physician had responsibilities towards the wife. Also, it was very important that I got there that Sunday afternoon to comfort and so forth. You cannot just leave such a case without sticking to it.

The reason I am very knowledgeable about this next case is that it was a lady who used to give me a lift when I was a medical student back in the early part of this century. The second thing is that the GP happened to be the cousin of the patient. For that reason, there was much more than usual documentation of the decision. I ask you to accept that this is a slightly exceptional situation, but welldocumented.

This was a woman who was actually a medical administrator. She developed a neurological situation in her 70s. She lived alone in a unit but she got around with some family assistance. In March 1993, she had a severe stroke. It knocked her sideways. She was unconscious, had no speech and could not swallow. Some 48 hours later, there was no improvement. At that point, I have to say that a lot of people would actually let somebody die. I must say that.

In this case, the GP and the doctors concerned were most conscientious. They sought formal ethical advice, somebody with philosophical intent and all that. I should say that I am not a philosopher. I am just an ordinary coalface doctor. Ethical advice was taken and they decided that a nasogastric tube should go down.

She was then cared for very well in a nursing home. Contrary to fairly common practice, the naso-gastric tube was left down. The common practice would be that, after a few weeks, a naso-gastric tube may have been replaced by a tube going direct to the stomach. But in this case, for reasons that are not known to me, it was not done.

---

The woman was cared for superbly, but she did not improve. She never showed any sign of consciousness. They thought she vaguely knew that family and nurses were present, but there was no possibility of her being questioned. Her general condition was fair but complications developed. When someone is lying in bed, it can do nasty things to their elbows. She became incontinent. This is all very sad, but I am afraid that it is a very common situation.

I had the permission of the doctor, but not the patient. He was concerned to share this; he just wanted anything from this case to benefit the human race. On 27 October, the naso-gastric tube fell out. The question was, should it be replaced? On this occasion, the doctor rang me up. We get lots of calls from country doctors as well as city doctors; it happens all the time. I was away, but I got the message that he wanted some help with the ethical situation.

Our community director went to see the patient. In a palliative care service such as ours in Sydney, we have people whose portfolios cover different areas. The community director, who I have to say is a generation younger than me, went to see the patient. Her judgment was that the tube was just prolonging the woman's dying. She felt that there was no need to continue doing that.

It was not a matter of not trusting my community director's judgment, but because of my personal involvement with this woman, whom I had not seen for 30 years, I went to see her myself when I returned to Sydney on the weekend. She did not know me at all. There she was, much more peaceful than before because palliative care nurses had been brought in to assist the nursing home staff.

The GP rang me and said: 'My wife and I are at peace about this. Thanks very much'. There is a funny paragraph following in this case; I put it in for honesty. He went to see her the next day. He sat beside his cousin's bed and she looked much more peaceful. He said: 'Can you hear me?' The tube was out, her throat was much better and he thought she said: 'Yes, I can hear you, John'. He rang me on the Monday night and said: 'I cannot believe it. But one thing is very important. She showed not the slightest sign of wanting the tube back'.

*Additional note: The primary ethical principle is to try to act as the patient would have wished if we can get any idea of this - from written directions, comments, or close knowledge of her personality.*

We do not know if he was imagining that or what. Certainly, she was clearly not struggling, asking to have the tube back. Keep in mind that this woman was a medical administrator. She was very comfortable and she died a few days later - 12 days after the tube came out altogether. No sedation of any sort was given. Just for the record, the sedation given in that last case would not have actually shortened his life. No sedation was needed here. She undoubtedly had mild hypostatic pneumonia in the end and she just drifted away.

*Additional comment: This woman's last 10 days of life were of better apparent quality than the previous weeks, and this peaceful period was of more value to her relations, to help them say goodbye*

Before my colleagues comment on this case, I want to comment on Dutch practice. It is documented. I happen to know the Dutch anaesthetist who has really led the vanguard in euthanasia there. In an article, he has written that he thinks that if a tube is taken out like this,

the patient should be terminated there and then on the grounds that there is no way the person can die with dignity. I am afraid that that is rubbish. This is just a clinical point, that a person can be cared for under such circumstances with dignity under intensive palliative care. You cannot do it with nothing, but in fact it can be done.

**Dr LIM:** I would just ask for some clinical information. Was she hydrated and fed in the last 12 days?

**Prof. LICKISS:** No, in this particular situation she was not. It was October. She had exquisite care to her mouth and she was not having any problems with hydration. You have asked a very important question, sir. Obviously, had it been January or in the heat, or had there been any problems with mouth care, we do occasionally use subcutaneous fluids to hydrate. As you would know, this is a moot point. It just might be the case in Darwin that you may need occasionally to give some fluids. Lots of research projects have been done. It is very hard because the people who have died cannot tell us the real answer. It looks as though discomfort is not correlated with dehydration.

Nevertheless, I have to tell you that in just a handful of cases in Sydney we would give subcutaneous fluid if we felt that the patient was in any danger of discomfort. Another circumstance where we would give subcutaneous fluid is if the patient had to be in a unit where intensive mouth care by a skilled person or by family could not be given. In a big acute general ward at Prince Alfred, we would be much more likely to leave a subcutaneous infusion or something like that going rather than risk it. Within a firstclass palliative care unit there is much less danger of that. It is a very controversial medical point.

**Dr LIM:** I am thinking about somewhere like Alice Springs, where humidity is less than 30%.

**Prof. LICKISS:** I have not practised in the Alice but my personal view is that you may be in the situation where, say, a litre or 2 of subcutaneous fluids a day might be needed to ensure comfort in such a patient.

**Dr WAKE:** Dr Kilburn would like to comment on that case, Mr Chairman.

**Dr KILBURN:** The reason we have presented this 2nd case is that it illustrates a couple more of the issues as distinct from the 1st case. In contradistinction to the 1st case, there was no explicit consent by the patient. This patient was not able to give consent. As a paediatrician, that is a situation that I sometimes face with the children I look after.

The other way in which this case differs from the 1st case is that a decision was made not to reinstitute a treatment that was already being given. It is not too far removed, and it is certainly a decision which is sometimes made, to stop a treatment if it is felt that the treatment is only prolonging the dying process and is not giving relief of symptoms, suffering or pain.

Once that decision is made, one must accept the obligation to provide good terminal care to that patient. However, that patient can be allowed to die or assisted to die with good terminal care. That decision is one which is currently viewed as being perfectly ethical within the medical community. It is currently available and used under the Natural Death Act. I think these 2 cases illustrate that the proposed bill would not add anything at all to their care. the 2nd patient would not come under the terms of the bill because they could give no consent, as paediatric patients cannot.

I think it is also important to realise that these are medical decisions which are currently being taken in an ethical manner. This is not euthanasia. I think that there is a very widespread public misconception that people's suffering is prolonged under medical care. In fact, there are already wellestablished ethical and legally sanctioned medical guidelines for the withdrawal of care to assist people to die.

**Prof. LICKISS:** After cases like that, there is a general feeling of ethical peace. There is grief that somebody has died but you do not have medical turbulence. I think this is an important point.

I now wish to put up our 3rd case which, I have to say, I find very distressing. The case was published last year in theLancet (May 8, 1994) a very prestigious medical journal, as you would know. A 64yearold man with a brain tumour was permanently unconscious with frequent seizures that could not be controlled. He was not on opioids morphine or anything like that. It was considered that no treatment alternatives or chance of improvement remained. This was confirmed by another physician. I have to say that the first part of that is not uncommon for people in that disastrous situation, but it is not very common not to be able to control fits. Nevertheless, that is not germane to the case. The issue was: what should be done in such a situation?

What was done was this. After discussion with a colleague, nurses and the patient's wife the main arguments being the very poor quality of life with no chance of improvement, further treatment being futile the specialist gave potassium chloride by an intravenous drip, and death ensued within 3 minutes. This was a case published from a Dutch inquiry on what is happening in Holland. It was published under the heading of, 'The situations where we feel justified in taking life without consent'. I find this very distressing. The spectre of that sort of thing happening in our hospitals, and the effect on the subculture, is grossly disturbing.

Let us take the positive side. What should have been done? What would have been done in any decent medical department? First of all, get more information about current therapy. There is an enormous amount that one needs to know about this whole case. Reconsider all treatment options. I am not saying that a patient should be sent from, say, Darwin to another city for more radiotherapy or anything like that. However, usually in a situation like that there is a lot more that needs to be considered and I just have to say that that is usually the case. I feel that this is a disastrous situation. I cannot pretend to sit on the fence about that. I think that approach is medically, psychologically and emotionally aberrant. A very different kind of turbulence occurs after that kind of event.

I know that there is sporadic, very occasional, euthanasia going on because I work in a hospital which has 800 beds and which used to have 1000. I also know the fearful turbulence surrounding such situations, as I have been involved in counselling nurses and doctors occasionally who have been on the edge of that. I also know their gratitude, when one can help them to avoid going over the brink into such a course of action.

9

---

**Dr WAKE:** Thank you. Mr Carson is going to comment on that case, Mr Chairman.

**Mr CARSON:** Thank you. I would make 3 comments. First of all, that particular case is not covered by the proposed bill because the patient was incompetent and not able to give consent. The bill will not help those very hard situations. I guess that is the sort of case that one might propose euthanasia legislation for. However, we would very much caution against that, in that it is a very difficult medical situation and a very difficult social situation.

There are many difficult medical and social situations. We often have our backs to the wall when treating diseases at the edge of our knowledge. This is even more so in the Territory, because we have a much smaller resource base in terms of specialists available and equipment available. So we are going to strike those problems more. However, we would submit that killing a patient, killing the problem, is not the answer to this lack of resources or to nutting out a difficult situation, for many reasons.

One of the potential reasons is a possible decrease in the quality of care. It takes the focus off trying to solve a problem with an easy 'kill the problem'. That takes the focus off relief of the suffering of the patient and the relatives, and emotional distress. It will decrease the need to develop curative and palliative services in the Territory because we have that so-called easy way out. I will leave it there.

**Dr LIM:** All that is fine, but you are ultimately producing pharmacological oblivion in a patient. What is the difference between that and the potassium chloride infusion? The patient is unconscious anyway. Sure, he is not fitting any more, which is terrific. Really, from some medical practitioners' point of view, there is very little difference between pharmacological oblivion and euthanasia, because they are in effect not functioning any more.

**Prof. LICKISS:** It is a very difficult question but I would assure you that I would see a profound difference. We look after people with cerebral tumours many times a year, just to take that example, and you basically have a human being dying in the midst of family. Occasionally there is no family but at least you have a person dying gently and peacefully of a disease process. You actually can control the manifestations. Existentially, the difference is profound from that sort of sudden and abrupt finishing off.

I do not accept all the talk about pharmacological oblivion. I must say that I find some of this terminology aberrant. There is a precision about modern palliative medicine. It is not just some blunderbuss of oblivion. I would have to say that one in fact would be able to control the fits of that man and to have him gently sleeping through the last days of his existence with his family holding his hands, dying peacefully. That is possible and it is done every year.

I could go on about it. I see a profound difference. There is a palpable abhorrence that one somehow senses in the face of this kind of medical practice. That is just not present when one has another kind of dying, with a sense of grieving but no sense of abhorrence. I am not saying that every scenario is easy.

---

**Mr POOLE:** It seems that, of the 3 cases you have presented, the only 1 that would be covered under the terms of the Northern Territory Terminally Ill Bill is the 1st 1. The others are well outside the guidelines and the fairly narrow constraints of the bill.

**Prof. LICKISS:** My reason for including the 2nd one is that I actually have had a lot to do with the Dutch situation. I had dinner with Prof. Remmelink 3 times and discussed it in great detail. The fact is that one has a package situation. Once the line is crossed, the whole package is there. It is not a slippery slope; it is just a package. In fact, in Holland, as I am sure you know from the statistics, involuntary euthanasia is much more common than voluntary euthanasia now.

**Mr POOLE:** Of course, they now argue about the statistics themselves. It has been put to us that there is some debate as to whether or not they are actually involuntary because, when the people were originally ill, they said: 'I do not want to be kept alive and if I reach that stage and become non compos mentis, I want you to put me down'. It is argued that that possibly artificially inflates the category of involuntary euthanasia.

**Prof. LICKISS:** One interesting point is that we cannot actually check a patient after they are dead. I do have patients that I am aware of, who have requested euthanasia and then some weeks or months later have thanked me for not going ahead with it although at the time they were quite vehement.

**MR POOLE:** It is a question that we ourselves have raised, as to whether or not, should the bill go ahead, it should be amended to give a coolingoff period.

**Prof. LICKISS:** You would have to.

**MR POOLE:** There are other things that are argued, that we ourselves have already highlighted.

**Dr WAKE:** We would say, Mr Chairman, that basically good medical practice plus the Natural Death Act are able to deal with all medical situations in an ethical and in an appropriate fashion. That is our belief.

**Mr POOLE:** Yes, but some palliative care specialists do say that there is a numerically small percentage that would not be covered. I think the figure we were quoted was about half a dozen in Adelaide last year that would not be covered. That is not to say that they would have wished to be covered if euthanasia was allowed. There were about half a dozen people in Adelaide last year, in palliative care, for whom nothing could be done. Their pain management had got to such a stage that they could not do any more.

**Dr KILBURN:** We all agree that that is a difficult and a distressing situation for both the doctor and the patient. We would argue that the benefits of allowing euthanasia for such a small group of patients would be far outweighed by the fundamental change that would be caused in the doctor/patient relationship. The doctor's job is to nurture, to help patients through illness, to help them through pain and to help them through suffering, but never to kill them. Once a doctor's job even in part becomes to kill that patient, we believe that the doctor/patient relationship can never be the same.

**Dr WAKE:** When euthanasia was introduced as an option in Holland, it was introduced as a very special and circumscribed option. Gradually, over years of familiarity with its use, it has now become a part of standard medical management. It is often, therefore, interfacing with a patient's wellbeing long before that person comes to any stage of terminal illness. Indeed, terminal illness is no longer a requirement for euthanasia under the Dutch legislation.

The 2nd case is 1 that I raise carefully and cautiously. It is abortion in this country. When the abortion legislation was brought in, it was very clear that it was to be circumscribed and to be used exceedingly carefully and sparingly. Gradually again, with familiarity, we have seen the intent of the legislation lost. I would say that the current abortion practice bears little relationship to the whys and wherefores of the Northern Territory act. Therein lies much of our fear. We believe that legalising euthanasia even for one person in the Northern Territory will, over the years, produce the same informality in the application of the act that we have seen in Holland and with the abortion law. Therein lies much of our concern.

**Mr POOLE:** What is the AMA's attitude? I note the comments that your president has made over the past couple of months with regard to his personal assisting of people. I guess that we have evidence that certainly some doctors up here in the Northern Territory occasionally practise euthanasia, although I qualify that very quickly by saying that it depends on your interpretation of what euthanasia is.

**Dr WAKE:** Absolutely.

**Mr POOLE:** It appears to be more likely that they are managing pain, and during that process the life period is shortened for whatever medical reason. I think that it is a very grey area. The argument, and I am an advocate of that, is that maybe it is better to have it all above the table so we know exactly what is going on and how many people are affected.

**Dr HOWARD:** I think under the current system people work very closely within ethical guidelines and at all times are answerable to their peers. They are answerable to their professional organisations, which are responsible for enforcing ethical codes of behaviour, and they are answerable to the Medical Board. What do you intend to replace that with? They will be answerable to no one?

**Mr POOLE:** Some would argue, including Marshall Perron, that at least in this instance you have 2 doctors conferring with each other and agreeing on the medical condition of the patient and the request by the patient. In the current situation, a single doctor might be administering something which that doctor considers to be in the best interests of the patient but ends up terminating life anyway. They sign the death certificate. They are the doctor looking after that person. There is no balance and check.

**Dr WAKE:** Mr Chairman, there are a great number of balances and checks within the system. I think that is what Dr Howard is saying. It is very unlikely that, in a hospital setting, you can get away with killing patients without someone knowing about that. We believe that any killing of patients in Australian hospitals is rare enough to be described as aberrant behaviour.

The published studies are ambiguous in the extreme, as you quite rightly pointed out. They contain no definition of euthanasia. The question asked is: 'Have you taken active steps to end a patient's life?' I believe that I can answer yes to that question, often. But I have never committed euthanasia. Many doctors are confused about what euthanasia is. I think nurses are even more confused, with respect. They are confused about what euthanasia is, and they are confused about the Natural Death Act. They are confused about their legal and ethical responsibilities to the dying patient. This is one of the major reasons why we counsel caution. Certainly, the AMA is not a righttolife organisation. We believe that many things need to be discussed. At the moment, so much is unclear and unknown and cannot possibly be known in the next 2 months.

**Mr POOLE:** You said that it would be very hard for a doctor or anybody else in the medical profession I presume to get away with killing a patient in hospital. What about the situation, as in many terminal cases particularly cancer patients, whereby people go into hospital in a place like Alice Springs, end up going to Adelaide or somewhere, come back and then go home because they have reached a stage in their treatment where nothing more can be done? They basically go home to die.

**Dr HOWARD:** There are still many observers in that situation. The family is usually very much aware of what is going on. Community health services are also involved and they are pretty astute as to what doctors are getting away with.

**Mr POOLE:** Do not take me wrong. Forgive me for playing the Devil's advocate.

**Dr HOWARD:** I do not think that Chris meant to distinguish between what happens at home and what happens in hospital.

**Mr POOLE:** I do not accept the argument that we have a horde of doctors out there, just waiting to run around and inject someone.

**Prof. LICKISS:** I think the news would get around very quickly. We have doctors out there who are very distressed and can put a tick against a questionnaire because they think that it is euthanasia, when in fact they are as clear as crystal in their intention that they are trying to reduce suffering and distress.

The clinical point is very important. Any palliative care specialist or cancer specialist can tell you that there are occasional patients whose pain is very difficult to shift. I have 1 such patient whom I will see within an hour of getting back into Sydney. In our big practice, we have a patient like that about twice a year. The only thing in that situation that one can

---

usually do is try to get the person sleeping. I can assure you that it is not a pharmacological soup or chemical oblivion. You can have somebody peacefully sleeping on that last day or 2 of their life. They know when a person like me goes to them. They know that one is present.

I have a frightful situation with a businessman back there now. In the 10 years during which I have been in fulltime palliative medicine, I have to say that I can remember about 3 patients like that. I shall not forget them it is too difficult. But one still is not definitely and directly trying to kill that person. I do not like the word 'kill', I must say. .You are not trying to eliminate them.

**Mr POOLE:** I think that is one of the problems in this whole debate. We were discussing it earlier today. It has taken 20 years for doctors really to stand up and start talking about killing people and people dying. 30 years ago, they did not even tell people they were dying. They gave them the pills or whatever and went away. They tapped the wife on the shoulder and Dad passed away.

**Prof. LICKISS:** I think the discussion about this bill has been very useful in so far as it is at least helping some things to be clarified. But I see a need for clarity with regard to the existing situation, much more than any question of moving from it.

**Dr LIM:** Dr Howard, you were talking about the scrutiny that one is subject to in a hospital setting where you have colleagues, nursing staff and health staff who are actually scrutinising everything that you do. At home, even though you have the community nursing staff coming in to visit the patient, a general practitioner can get away with a lot more. In fact, providing a lethal dose of any drug within the home setting is much simpler than in hospital and under a lot less scrutiny, as the general practitioner signs the death certificate. There is very little control over the falsification of death certificates. It does happen, and people get away with it scotfree.

**Dr HOWARD:** Yes, but do you really believe that is common behaviour? The point we are trying to make is that in the main there are ethical constrictions upon us. We are creatures of ethical discipline. It is highly unlikely that any significant behaviour of that sort is going on. What certainly happens is what Chris has said that people see the end result of their treatment resulting in the earlier demise, perhaps by hours or a day at the very most, of a particular patient. They may in their state of confusion tick yes on a euthanasia questionnaire. I think that is much more common.

In relation to the comment about doctors only just becoming upfront about death and dying, doctors are creatures of the same society as our patients. Particularly in AngloSaxon Australian society, death and dying have been hidden from everyone involved for generations. Patients, doctors and relatives are learning to be much more upfront about it.

The changes in practice in care of terminal patients in the last 5 to 10 years have been phenomenal. It is so much easier now to manage terminal patients because people are aware of the fact that in general you can sit down and talk with your doctor about it. It is no solution

---

just to say that it is all too hard and we should knock them off quicker. That is not the solution. We are all on a learning curve. We have all come a long way in 10 years. The best thing for us as a society is to continue along that learning road and improve our skills and communication, not to just put the problem out of sight in a box.

**Mr STIRLING:** Could I go back to the 2nd case that you quoted? It disturbs me somewhat that it is a case that would not qualify under the bill, because the person was not competent. I just want to be clear that, when the tube came out, that person then survived another 12 days without any food, nutrition or water.

**Prof. LICKISS:** This was the point I was making, that in fact experience shows that people can be cared for. She was in a much better state after the tube came out and during that 12 days than she had been in the previous several months. That was the nursing staff's appraisal and her cousin's appraisal also. You certainly can keep human beings comfortable without exogenous food, without food and nutrition. Provided that it is not too hot and you have exquisite care, you can keep people alive and comfortable without fluids. That was the substance of Dr Lim's point.

It certainly can be done and is done hundreds of times a year. But you require highly skilled nursing practice and highly skilled medical practice. You know that if somebody had no food and water out there in the desert, they really would die a very difficult death in a few days. It is a very different thing in a hospital ward. All I can say is that the assurance is there that that is not necessary. You also heard me say to Dr Lim that there are situations where sometimes one does give some additional fluid, especially if the nursing care is not of adequate quality.

**Mr STIRLING:** This is a strong case for me. In fact, I think it is a case that proponents of euthanasia could readily put up in favour of their own point of view.

**Prof. LICKISS:** Could you explain that?

**Mr STIRLING:** I can see that it has taken 12 days for this person to either starve to death or dehydrate.

**Prof. LICKISS:** No. I think you are painting a portrait that is just not the case. The image you are giving is not the case. You are dealing with somebody who is peaceful, who is just vaguely aware. Most people who have got up and walked after strokes can in fact tell you they were aware of their environment. She was gently and peacefully sleeping through the last week of her life. The family is getting through the grieving. I think it is very important that they are not being caricatured there. The situation is peace and calm and dignity. That is all I can say. The caricature would worry me more than it would worry you.

**Mr POOLE:** In your submission, you make fairly strong comments about things that are not covered by the bill anyway. One presumes that the major point of the AMA's resistance to the passage of this bill is the sanctity of human life and all those sorts of things. However, if you take out of the submission all the comment about the things that Marshall Perron's bill does not allow, it is really quite a thin submission.

There are some key points in it. In respect of the sanctity of human life, it says: 'This means that life cannot be taken away from someone. It also means they cannot forfeit their life. This is clear to all of us when we consider our dismay at the rates of youth suicide in Australia. It is clear that the law makes assistance to suicide a criminal offence'. Well, the Northern Territory is the only jurisdiction in Australia which makes assisted suicide a criminal offence, and we are going to repeal it, anyway, because it is outdated.

**Dr WAKE:** Certainly, many aspects of that submission are not particularly relevant to the bill, which is, of course, why we would like to talk to you about the bill today at length. I think I take that point, but I think you should take the point, as Prof. Lickiss has pointed out, that we do see this as a package deal. We believe that the whole purpose of this legislation is to establish a view within the community that under some circumstances life can be taken. We find that offensive, and that is the purpose of the submission. On that basis, I think it is a fairly thick submission.

**Dr LIM:** The submission makes reference to 3 decades of change. I query the statistical figure that you use where you say that, at the last Australian census, 82% of the population of the Northern Territory held that they had religious affiliations. I suspected that the figure was a little high, so I checked up on the ABS figures. The Christian population is about 64.6%. Although 18% indicated no religion, another 13.7% or 14% did not state any religion. So would you be happy to accept 65%?

**Dr WAKE:** I do not think that I would, Dr Lim.

**Dr LIM:** Let me show you the list of the stats that I got, okay?

**Dr WAKE:** They do say strange things about the Territory.

**Dr LIM:** If you took out the no religion at 18%, then 82% by inference have a religion.

**Dr HOWARD:** There are other religions apart from Christianity.

**Dr LIM:** Yes, it is all stated there Buddhist, Islam, Judaism, other. There is another group called 'not stated'. Neither you nor I can assume they have or they do not have a religion. They are not stated. That is 14%. I suggest to you that we should take that out of the equation, yours and mine,

**Dr WAKE:** I was unaware, I must say Dr Lim, that there was a notstated group, in which case it is a matter of 'mea culpa'.

**Dr LIM:** Our figures are then clear, okay? Thank you.

**Dr WAKE:** Okay, thank you very much. I think the point still stands that religious affiliation within the Northern Territory community is in fact in the predominance. I therefore think that, as some would argue, marginalising the churches on the basis that they are now irrelevant is simplistic.

---

**Dr LIM:** I accept that.

**DR KILBURN:** Could I go back to the point that you made earlier about the proposed bill having checks and balances, where 2 medical practitioners need to agree to the termination of life? If in fact you are talking about GPs working by themselves out in the community administering substances to kill a patient, then there is no guarantee that such a doctor is going to talk to his colleague about it. It is not necessarily true that that provides a check or a balance to that behaviour.

**Mr POOLE:** I would suggest that Marshall would argue on the basis of: why would you break the law when you can do it legally? You could conform to the requirements of the bill and not take any risks at all.

**Prof. LICKISS:** The evidence from Holland would indicate that legality is not influencing a lot of people's practice.

**Dr WAKE:** My own experience in South Australia is that the legality is not a consideration. Doctors act out of compassion.

**Mr POOLE:** If you read the whole of the Dutch report, you will probably say that it is in favour of the system. It is quite remarkable that people are not walking down the streets with banners saying: 'Let us stop all this nonsense'. I know there are organised groups.

**Prof. LICKISS:** There are individuals and I can assure you there is great disquiet, as you would know. You must have read the report of the House of Lords committee, which left Holland with great disquiet.

I attended an inquiry last year. A colleague, who is the head of surgery in Royal Brisbane Hospital, said that a friend of his had just left Holland. He stood in front of a microphone and said that a surgeon friend of his had been asked to see a lady in outpatients clinic. She was an ancient lady, older than me, and she had cancer of the tongue. He thought that he could help her. He booked her in for surgery and was told that he was not allowed to do surgery on her because she had to be terminated. He was sent a counsellor. He packed his bags and left Holland.

The climate is very worrying. The European Association of Palliative Care, most of whom are cancer doctors who live around the borders of Holland and are very aware of what is happening, have put out quite an authoritative statement that they do not think euthanasia is the way ahead to improve patient care. A similar thing has occurred among the Canadians, who are just as removed from Holland as we are. I think it is very wrong to think that there is no disquiet. There is extreme disquiet.

**Mr POOLE:** I was aware that there is disquiet in Holland. I was certainly aware of that. What I was trying to imply was that, if it is such a terrible situation in Holland, one would think there would almost be revolution on the streets to change it.

---

**Prof. LICKISS:** Of course, a lot of people who have been at mercy of the system cannot talk. That is one thing. There really have been a vast number of people who have had their lives truncated. They cannot give evidence.

**Mr POOLE:** I would like to think, though, that if I was knocked off by a doctor in Holland, my family might be annoyed about it.

**Prof. LICKISS:** You would like to think that.

**Mr POOLE:** I would like to think that.

**Prof. LICKISS:** There are families who are distressed about it, and there is a great deal of concern.

**Dr WAKE:** Mr Chairman, time is getting along. We would very much care to go through this bill with you. We will be as quick as we can under the circumstances. Basically, we have something to say about most of the clauses as we go through. Perhaps we will point out the clause and move along in discussion as we go. Professor Lickiss would like to talk about the interpretation of the word 'assist'.

**Prof. LICKISS:** I think that has been covered. I just cannot stand seeing the work 'assist' being used for putting people to death. Assisting means a lot of things. If someone asked me whether I help people die, my answer would be that I hope I do, although a 3rd of the people I see are still alive a year later. I think that has already been covered.

**Dr WAKE:** I wish to speak to part 2, 'Request for and Giving of Assistance', clause 3, and in particular to draw your attention to the lack of definition of what terminal illness is and the 12month period. Now, 12 months is an extraordinarily long time in the life of a cancer patient or someone suffering HIV disease, for instance. We believe that the probability of someone suffering severe pain, distress or other suffering, that length of time distant from their death, is likely to be highly remote. A person requesting euthanasia at that time is highly likely to have other motives. For instance, they may be depressed.

As a publication in the British Medical Journal of October 1994 indicated, they may be responding to family pressure. Elderly people, in particular, when they request euthanasia, often have fear of dependency in mind. It is not fear of pain or suffering. They will be fearing becoming dependant upon family. It is interesting to note that the same study demonstrated that, while requests from patients might occur in about 4% of cases, requests from family were around 28%-30%. The researchers concluded that people might well be concerned, in the case of the aged, that those who no longer had an investment or an interest in that person's longevity might be using persuasive means.

**Mr POOLE:** We have already identified both those points.

**Dr LIM:** What about the fear of dementia?

---

**Dr WAKE:** In the HIV group?

**Dr LIM:** In any instance, even with metastatic carcinoma with cerebral secondaries, dementia might occur at some time during the terminal stages, whether it be 12 months or 2 years. What happens then? Would you allow a person to have a longer buffer so that they can at least make up their mind before dementia sets in?

**Dr WAKE:** If we are going to have this bill, I am not sure how long that period should be. I would say that, in the vast majority of cases, 12 months is an extraordinary length of time.

**Prof. LICKISS:** Is it not possible within the existing situation for a patient to talk it over with the doctor and say: 'For goodness' sake, if I start to go off in that way, please do not do anything that will prolong my life. Give death a chance the first time it turns up and let us just walk into this as a partnership'. It seems to me that the existing law is so superb that trust and partnership can exist and take care of those frightful situations. I obviously have experience of treating patients with AIDS, although I gather that this is less familiar up here. I would have thought that the existing legislation is superb and, without all these other fearful emotional overtones, that partnership of trust should be able to take care of this sort of situation.

I have told all my young doctors that, if I start getting a big brainstem stroke, I do not want anything done about it. I do not even want a naso-gastric tube put in. I have said it and I have written it down. I really do think that is the sort of thing that should be able to be honoured.

**Dr WAKE:** As regards the definition of terminal illness, I think most people in the community can readily identify terminal illness with malignant disease. Perhaps some of us can think in terms of HIV disease as having a terminal phase.

One of our major concerns is that nowadays, the majority of requests for endoflife decisions come from the frail, aged, socially isolated people within our community. That is the case in my practice. These are not people with malignant disease at all. Now, these people with degenerative diseases, such as chronic airpassage disease and cardiac disease, are very easily put into this prognostic category of being likely to die within the next year of a terminal illness, which is indeed their heart or their lung disease. Indeed, we believe that it is far more easy to prognosticate on this basis for an 80year old than it is for the average HIV sufferer or cancer patient. We believe, therefore, that there is good reason for the elderly group within our community to be concerned about the lack of definition of terminal illness. I do not believe the draft intends that these groups should qualify.

**Prof. LICKISS:** We need to remember that some of the elderly in Holland have credit cards which say: 'I do not want euthanasia'. It is true.

**Dr WAKE:** 2 gilders 50.

---

**Prof. LICKISS:** I did not want a price on it, actually.

**MR POOLE:** It is an area that we have identified ourselves as well.

**Mr CARSON:** To reiterate a point that has been made, the raising of a request by a patient to a doctor fundamentally alters the doctor/patient relationship, especially if the doctor feels unable to comply with the request. This is even more so in the Territory, where the doctor is more likely to be isolated or out of the major towns. Even in our largest city, Darwin, there are only 2 or 3 of each particular specialist. If the doctor does refuse that request and the patient continues to ask him, it implies a handover of the patient in this critical stage of their life to another practitioner. In a smalltown situation, it is obviously going to cause tremendous disruption of the doctor/patient relationship if the doctor continues to refuse.

**Mr POOLE:** I sometimes wonder about such comments, which I have heard since I have been a member of this committee. I wonder whether that is really becoming a convenient story for the doctors, rather than the patients. If I wanted to die and I was terminally ill, it would not upset me if my doctor said: 'I am not prepared to be part of this, Eric. I will have to get Fred to come in and look after you'. I suggest that maybe this medical professional business upsets the doctor more than it upsets the patient.

**Prof. LICKISS:** I think that is a very deep thing that you have said there. We do have a sizeable number of people who, on first consultation, say that they would really like to die. One old lady said: 'I would like my train to go out of the station'. That is a very deep thing. But it is extremely rare for a patient to request you actually to do something. That is so rare that I can remember the times when it has occurred in my professional life. One listens for it, but it is very rare.

With your personality, which is probably like my personality, if you were in a country town and wanted to make really sure that no one did anything to prolong your life, would you not accept a doctor looking you in the eye and saying: 'I promise you that I will look after you. I will make sure that nothing is done that will prolong your life. If you get pneumonia I will care for you and we will not try to bail you out of it. But I am not going to suddenly do something that will terminate you'? Would you trust that doctor?

**Mr POOLE:** I think it is a debatable thing. I say that because, although there are probably no statistics, I wonder how many people actually die in the company of a doctor who is really familiar to them. I shall say this just out of the blue sky. I think that probably doctors and patients form that relationship in the last 6 months of their lives anyway. It is not like the old days.

**Prof. LICKISS**: Even in the context of that 6month relationship, could you not accept that a doctor could look you in the eye and say: 'No, I am not going to put you down but I really will promise you'? I have looked patients in the eye so many times and said that. I have sat beside somebody's bed and said: 'I promise ...'

**Mr POOLE:** That is part of Marshall Perron's argument of course...

---

**Prof. LICKISS:** What do you mean?

**Mr POOLE:** The doctor looking you in the eye and saying: 'Look, I am sorry. I cannot do what you want me to do'. It might be because it is not legal or whatever. 'I refuse to partake of that provision of the act but I will look after you'. Perron's argument is that that is not good enough, because I want to die.

**Prof. LICKISS:** I think there are 2 sides there. It has to be brought up. One is that you cannot have a patient or a person or any of us insisting on something. A right always implies an obligation. No man is an island. You cannot have a right in isolation. I think that is actually where we need wisdom. You have a wish to die. You do not want to keep on going. You cannot force society to honour that risk. In my view, however, you have a right to demand that your doctor listen to what you are saying and recognise that within the ethical limits of existing practice and the marvellous Act (Natural Death Act) you have up here, he or she will not do you medical mischief by giving you more and more stuff and more and more tubes to keep you going. I think that is medical mischief. I think that is really the wisest approach, even given your prejudices and my prejudices about wanting our own way.

**Mr POOLE:** Sure, but I would also suggest to you that if you were my doctor and at the end of day I told you that I wanted to die, if you did not think that was the right course of action for me, forgetting the ethics of the situation and the position you are arguing today, then you would say: 'Eric, don't be silly. You are going to be around for another 6 months or whatever'.

**Prof. LICKISS:** I would not say that to you. I would say: 'I'm here with you, and I'm going to stick with you'.

**Mr POOLE:** Do you not think that, if this bill was passed and became law, the average doctor ...

**Prof. LICKISS:** Surely not this bill. I mean, this bill is just too horrible to even think about.

**Mr POOLE:** You never know. If this bill became law, we might be talking about 12 or 14 people a year within its narrow confines. If that situation did arise, a lot of people would actually reconsider and decide to die naturally or and I am not trying to offend doctors would be talked out of it by doctors.

**Prof. LICKISS:** I think you are right that a lot of people would change their mind. I know the argument, because I have had to think about it. I know the argument about a sense of a climate of freedom, and at least the option is there and one can decide against it. I think that that is a superficial argument. What in fact would happen is that you would change the basis of the relationship. This is an earthshattering consequence. It is not just tinkering around the edges. It is a fundamental shift.

---

**Mr POOLE:** Earthshattering things have happened in the last 20 years. Reference has been made to the abortion debate and the changes in the law. That to me is an even more dramatic thing because it affects somebody who has not had the opportunity to be asked for permission.

**Prof. LICKISS:** That is true.

**Mr POOLE:** It was an even bigger thing but it has happened and our lives have changed because of that.

**Prof. LICKISS:** I think you are really talking about what sort of future we really want. I think that what you are saying is terribly important, but to go for this kind of procedure ...

**Mr POOLE:** It is no reason to knock the Northern Territory bill back unless you are knocking it back because it is a bad bill.

**Prof. LICKISS:** I think it is a bad bill.

**Mr POOLE:** Tasmania, the ACT and everybody else is queuing up now. I am quite sure that, whether this bill goes through or not, at the end of the day you are going to see a bill go through somewhere.

**Prof. LICKISS:** We just have to improve the care of our people. We have to improve the level of listening that is going on. We have to improve the autonomy etc. That is my absolute conviction, having practised more than he has and everybody else here, since 1970 in cancer alone. Looking around the room I cannot see through my back I think I am the oldest one here. Statistically, I am the most likely person to actually have to face some of this stuff.

I do not think it in the interest of the future of Darwin or Australia for anything like this to go through. I think we have an enormous obligation to use existing laws and the expertise in our community much better. We have to clarify that mess out there, of doctors and patients not understanding their rights and the possibilities within the existing situation. I have said too much.

**Dr WAKE:** I would just like briefly to take up your point that not many patients die with their hand being held by a doctor they have known for a number of years. I do not believe that is correct. I have practised now for nearly 20 years in this town, and I know Richard Lim must have the same experience. I would say that 50% of our non-Aboriginal community and I am sure that Dr Howard and Philip will back me up have very longterm relationships with their doctors and will often pop up for quite inappropriate things. People come to me and casually talk about strange things. I know that Di has people getting in touch with her for all sorts of nonphysician type things. We do say that this has grave potential to distort those longterm relationships. I would feel very sad to have someone that I have cared for 20 years say to me: 'You must do this for me'. I would be obliged to say: 'I cannot do that'.

---

**Mr POOLE:** 50% of your patients are much younger than you. You probably delivered them into the world as babies or whatever. On the law of probability, the chances are that you will not be standing beside their beds when they die. You will have long passed on and somebody else will have taken your place. All I was trying to indicate was that, to me, this doctor/patient bond is not the ultimate thing about the argument.

**Dr WAKE:** Certainly, certainly.

**Mr POOLE:** I still have the impression that it offends the sensibilities of the doctors more than those of the patients. It is something that is really worrying the profession. I just wonder about that. It would be nice to get some quantitative research done.

**Prof. LICKISS:** It is a legitimate worry. I mean, you want your doctors in solidarity. If you are going to design the ideal community for the Northern Territory, you would certainly want your doctors in solidarity and comfortable, sharing stresses as they do, all with our backs to the wall, all with failures, all with great difficulties. But you would not want to bring down a curtain between doctors. That is what this would really do.

**Dr HOWARD:** I think the doctor-patient relationship is important for patients. I get to see a lot of people in this town in a situation where I am the 1st person to have to tell them what they are facing . It is not rare to find that they do not even have a GP. This is what you are getting at. They have been well, until suddenly they are confronted with the fact that they are going to die. It takes a lot of hard work and thinking on my part, and discussion with the patient and their family, to find out what their requirements are.

I then negotiate on their behalf with a GP, and I will literally bring them together with someone who I think will answer their needs. They then very quickly establish a close, trusting relationship with that person, who is going to support them and their family through the weeks and months ahead. The quality of that relationship is terribly important to the patient and to their family. If you add this extra factor, I do not know how you could ever form that sort of relationship in a hurry at the last minute under pressure, which is what you are trying to do.

**Mr POOLE:** I am not trying to dispute the relationship at that stage of the terminal illness. All I was trying to dispute was the notion that these are longstanding relationships over 20 years, because I just do not believe it. I am sure that a fair percentage will but, as I said, 50% of the patients are going to be younger than you and whatever.

**Dr HOWARD:** A large percentage of those patients do create relationships that might as well have been there for 20 or 30 years, in terms of the trust and mutual acceptance that they produce within days. We are lucky in this town. We have a large number of young, very earnest, sincere GPs who take on this ...

**Mr POOLE:** I still go back to something which I guess forms the argument of many of the people who support the bill in terms of the rights of the individual. I am sure that those people would not like to see the bill fail because of the sensibilities of the doctors involved.

---

**Prof. LICKISS:** The bill requires doctors' involvement. That is the only catch. It is actually a very serious point. You cannot have this in isolation. No man really is an island. What strikes me, coming from the other side, is this concept of an isolated person like a shag on a rock saying: 'I want something, I want something, I want something'. This is really very frightening. I think that there are serious limits to the autonomy that we, as human beings in solidarity with our fellows, can demand. That is my real position in this. I do think that there is a serious limit to what we as a human being can ask of another person and of society in its support of us. There are some things we can ask, and other things we cannot.

I think there is a difference in kind here. It is not just a qualitative difference. It is a profound difference. We are crossing a river. It is something very, very different. That is my earnest comment. I just do not think religious issues are at the core of the opposition to this thing at all.

**Mr POOLE:** No, I think we all accept that ...

**Prof. LICKISS:** It is a very profound existential ...

**Mr POOLE:** Yes. I am quite sure, though, that there are many people in our society in the Northern Territory who, simply because of religious significance, will not have a bar of this bill, and we accept that. And we have had numerous indications from Aboriginal people that they will not have a bar of it on cultural grounds.

**Prof. LICKISS:** Palliative medicine specialists worldwide just will not have euthanasia as part of palliative care. I say that very carefully. I really do know the leaders in that. There are papers that can be tabled, Canadian doctors are quite clear, and there are long lists of signatories. One of the exceptions in the whole world are the doctors that emanate from Adelaide. I think it is very important for you to realise that that is absolutely exceptional. Adelaide is a beautiful city, but it is a very different situation with regard to palliative care. The Sydney doctors feel very strongly about this, and it is one of the difficulties we have. But the UK and ...

**Mr POOLE:** Yes, but bear in mind that we have had submissions signed by 60-odd doctors and 90 nurses in support of the bill.

**Prof. LICKISS:** You would get doctors in support of it. I am just making the point from a palliative care doctors' point of view, which is one part of my life. I think it is very important to realise that it is an absolutely exceptional situation.

**Mr KILBURN:** No. 5 in the bill, the response of the medical practitioner etc., not to be influenced by extraneous considerations this seems to us to place perhaps an unwitting constraint on people to voice their objections or their distress with the decision of a person to go ahead and use the bill. For instance, in the 2nd case, the wife who was very much distressed by her husband's expressed wish to die and to go through that process, may be constrained by this clause in talking to the doctor about that. That has important implications

---

in terms of counselling the relatives of dying people. We certainly would respect the right of somebody to request that no extraordinary treatment be given to them, but their relatives' wishes are an important part of that, both to the doctor and as a therapeutic part to the relatives. We would just worry that that, unintentionally, would place some constraints on the relatives.

**Mr POOLE:** It is obviously designed for a specific purpose, to stop people making a quid out of it. I am talking about from an inheritance point of view or whatever, doing a deal with the doctor.

**Prof. LICKISS:** That is a fascinating business. So you can stop somebody buying a house, try to persuade them not to buy a house or enter into a mortgage, but you are not allowed to try and stop them wanting to die.

**Mr POOLE:** Yes, but I think we are taking the literal things there. But it is certainly an area that is worthy of a second look.

**Mr WAKE:** Does it outlaw protest, Mr Chairman?

**Mr POOLE:** No, not at all. I don't think so. It is just for the purpose of compelling or persuading.

**Prof. LICKISS:** I think that also is very difficult, because again, not one of us makes decisions without extraneous considerations. We would not buy a car, we would not enter into a mortgage, we would not make our will, usually, without discussing it with somebody. The concept that we really can make a decision without extraneous considerations is very strange.

**Mr KILBURN:** I think that goes on to the next part, 6, conditions under which medical practitioner may assist; 6(a) the patient has attained the age of 18 years. While all of us are against the legislation none of us thinks that euthanasia should be legalised it is interesting to speculate why this group of patients has been excluded. I believe this addresses the whole issue of consent and autonomy of consent.

I suggest that children and adolescents under the age of 18 years are capable of giving consent, and I would contend that they are excluded because of the perceived vulnerability and their susceptibility to outside influences, so the consent they give may not genuinely be their consent. But all terminally ill or aged and infirm people are similarly vulnerable. I think children are just the same as everybody else, and there is no logical reason to exclude children from this bill because they are still capable of giving their consent. This raises the whole difficulty of how much a person's consent is their own. I think that children have been excluded from this because the people who have framed the bill do have some moral misgivings about the whole process.

---

**Mr POOLE:** The reason was given in the second reading speech, actually. It is the legal age of consent. That was the reason that Marshall Perron gave. I do not think there was any ulterior motive there, but the comments you are making will certainly be relayed to the other parliamentary members. That is what we are doing today.

**Prof. LICKISS:** It is an interesting concept in logic that the bill really seems to have 2 feet. One is the concept of autonomy and the other is suffering and the link between them. In fact, autonomy is not taken to its logical conclusion. Neither is the issue of suffering. It is only in certain circumstances, where they are being brought together, where it comes in. It is a very interesting logical question which I would like to see philosophers argue about. It is very strange there are a lot of people suffering.

**Mr WAKE:** Section (b) we have already discussed, I think, Mr Chairman. The question of terminal illness and likely to die within 12 months.

**Mr CARSON:** Can we just emphasise that point, though, Chris? I think perhaps that is where an expert group can emphasise the lack of certainty of both diagnostic and prognostic processes. I think it is true of any area you get into: the more you understand, the more you realise just how much you do not understand. I emphasise we usually get it right diagnostically, but often a diagnostic thing is made on the shadows of an Xray, and even pathology is not 100%. So there is a possibility of getting diagnosis wrong.

Certainly, when it comes to prognosis, we are working in statistics and conjecture. There are scientific bases for it, but even if I say you have a 99% chance of being dead in 1 year, if you are that 1 person who is not dead, you had a 100% chance of being alive in 1 year. You are not sort of 99% dead. So for the individual, we cannot give an accurate prognosis. The outcome of the bill is terminal, is final. So if you get it wrong, there is no comeback.

**Mr WAKE:** Section 6(c), Mr Chairman we have 2 situations where we have a 2doctor rule under Northern Territory law at the moment. One is the Cremations Act, where 2 doctors have to sign the documentation, and the other is the Abortions Act. We submit that in both of these situations, familiarity with the law has led to a degree of informality.

Certainly and I think Richard may back me up in the case of abortion law, which states you need 2 doctors' opinions, there is no such thing. All it is is the referral, as for any other condition, which is accepted as tacit agreement that this is appropriate behaviour. There is no discussion in these matters between doctors, and certainly no significant examination. All there is usually is a patient request.

In the case of cremations, the 2nddoctor rule also is used very informally. I put it to you that a doctor can ring Dr X and say, 'Would you just come and sign this document', and Dr X knows very little about the patient concerned, if anything, and the paperwork is signed.

We are concerned that the 2doctor rule is not adequate if this bill becomes an act within the Territory, and as medical practitioners become familiar with its use, we believe, the

---

2doctor rule will not be an adequate rule. We would like to point out some other factors about the 2doctor rule. If the 2nd doctor thinks that the application for euthanasia is inappropriate, does this mean that the treating doctor can then take another 98 opinions until he finds the 1 that is going to agree with him, and the job can be done? Clearly, one might just revert to having 1 doctor, making the decision as he has always done about his patient's well-being.

We believe that if a 2nd doctor has a dissenting opinion, then some type of conflictresolution system needs to be in place. We do not believe it is appropriate, beyond that 1st negative opinion, to go and ask a host of others. There needs to be some sort of tribunal or referral system which can look at this.

This also is very relevant, of course, to the situation where family members as they undoubtedly will feel very unhappy about the decision. If Mr X wants to do this thing but Mrs X says, 'Well, he's not feeling himself today', then, clearly, there needs to be some conflict resolution within the system.

**Dr LIM:** Proponents of the bill will suggest to you then that Dr A would not proceed with the process, because somebody has queried the competence of the patient.

**Prof. LICKISS:** But that is not what the bill says. The bill says all you need is a 2nd signature.

**Mr POOLE:** Yes, we have highlighted it. There are other situations, too. Would it be appropriate for 2 doctors who happen to be husband and wife to be signing, which could quite easily happen in a small area.

**Prof. LICKISS:** It is not even involving conferral with the carers, the family or anyone.

**Dr LIM:** Yes, (k) does that.

**Dr WAKE: I** think the other aspect that we should be aware of is that, certainly in hospital practice, doctors function in a hierarchical system. With respect to Mr Carson, if he tells his junior houseman to sign this piece of paper, it is extremely unlikely that he will say: 'No, sir'. So we do need to give some consideration to the relationship between these doctors.

**Prof. LICKISS:** And their seniority. 2 RMOs could do that**.**

**Dr WAKE:** These jobs tend to fall to very inexperienced doctors. They get most of the horrible jobs, and I have concerns about young doctors. You probably saw the Dutch euthanasia program on Channel 8. That really said to me that we will have problems with our young doctors and nurses who are involved in this behaviour with posttraumatic stress illnesses, and I think you should be aware of that. I think back to my early days as a doctor, and I did some things which were quite bizarre. As knowledge grows, as one comes to the

---

point of being 45 or so, one looks back and says: 'That was not appropriate behaviour'. I believe that some of our young professionals could well be injured by this act. I just wish to make the community aware that that is our view.

**Prof. LICKISS:** We have actually had a young Dutch doctor in Sydney at one of the hospitals I am associated with. As soon as a patient vaguely started to deteriorate, this doctor just wanted to write down a sledgehammer. The doctor did not see it as an ethical issue, because of being brought up through the Dutch system. It just was not an ethical issue as to whether in fact you gave a lethal injection or not. That was more frightening than somebody suffering from posttraumatic stress syndrome, actually to cease to even see the gravity of what was being considered.

**Dr HOWARD:** Even the Cremations Act does specify certain criteria that the signing doctors must satisfy in terms of years of graduation, seniority etc., before they can sign those. But this act does not specify anything.

**Prof. LICKISS:** I have been asked to comment on the next few clauses. I wonder what more I should say about these issues. I have already said that with regard to the illness causing the patient severe pain, really no man is an island. It should not be seen in isolation.

The issue of suffering, I think, is a separate issue. It is a very interesting point that suffering is probably best defined as a sense of disintegration of the self in ordinary parlance, we feel like going to pieces. But suffering is a very interior, core thing. We actually did a study on this some years ago. Sometimes a patient can name something that they think is the source of their greatest sense of going to pieces, sometimes they cannot. Suffering is a very deep issue. It is pretty immeasurable the Dutch actually conceded, at a very important meeting, that you cannot measure suffering. You cannot even discuss when suffering is unbearable. But I think this is a little bit peripheral.

On the issue of the medical practitioner informing the nature of the illness and its likely course, I have seen some absolute travesties on this. I have seen patients who have been told that they have metastatic cancer ... I had 1 woman who was not very sick and said: 'Doctor, I just want to die'. I asked why. She did not speak English, which is a very common situation in central Sydney, so we had to sort it out. She said she thought that she should want to die, because she had just been told she had cancer. She had hardly any symptoms from it, and did not feel sick from it, but she had been told that she had an advanced cancer and she just thought should die. A few months later she was able to joke about that. She is still going, and that was some months ago. She thought she should die: just because you had cancer, that is what you did.

It is really very complicated. The nature of an illness you can put a label on itand iIts likely course you can have some sort of estimate of that. But everybody is different, and the statistics prove us wrong. I speak as a cancer doctor there. I tell you, you just fall in.

---

You consider the medical treatment that might be available, including palliative care. I think palliative care is better thought of as 2 separate things. One is palliation that is, the clinical science of how to sort out and relieve people's symptoms and assure care. We are all involved in care the neighbours, everybody. But palliation actually has different levels of specialisation in it, and it is really a science of its own.

I do not know whether you want to take that up in discussion. Whether it (good palliative care) is available, I gather that is quite an issue in the Northern Territory, but it could be readily rectified with this level of interest and expertise. I think that Marshall Perron should be congratulated on having taken a step that has actually raised discussion about these things. This is really most important. He has raised some stuff that needs to be talked about. And how rapidly theTerritory could improve its palliative care facilities! I see it as a very real possibility.

It says here, 'no medical treatment reasonably available and acceptable to the patient'. The 'acceptable' is interesting. You get an occasional patient who will just say: 'I want to die, I want to die, I want to die, and I don't care what you're going to do'. Now, that is very rare. It is a very difficult situation. If you had somebody who really, absolutely, refused to have anything that the Royal Darwin Hospital could offer, or the Territory health system, and just stood up in the middle of the marketplace and said, 'I want to die, please finish me off', that is actually very difficult, I think, to cope with, quite frankly. But I do not know what those words mean, and I do not think I really want to say much more about it.

One of the things not mentioned here at all is the issue of depression. The research that is available indicates that most human beings really do want to live. When a person says they would prefer to die, there seem to be 3 or 4 reasons. One sort of person has a sense of biological completeness like my dad, who died last year at 94. He said: 'I've had a very good innings. One of these months, lass, something's going to happen to me. Don't you be upset'. That sort of sense of completion is, I think, a very, very precious thing and one respects it. The Aboriginal people are superb in understanding that, and we are learning.

The 2nd group are the people who are so distressed, for some reason or other, that they do not want to live. In Sydney, sometimes, financial troubles make them request or jump out of buildings. At other times, symptoms can be very distressing, and at least 90% of symptoms can really be shifted by contemporary palliative medicine. There is still a residue where you have great difficulty. But there is no question that good palliative medicine can make a difference.

Then you have a 3rd group where it really is the issue of autonomy. We have actually looked at this in Sydney. In the AIDS area, one does see the issue of autonomy as driving the wanting to die. This is a very painful thing. No matter what you want to do, you have this sense of an exercise of autonomy pure and simple. Now, a lot of those people, as they have someone walking along with them, actually change. There is one guy in Sydney now who, a couple of weeks ago, was all for autonomy. 'I want to die, and I want to die when and how I want'. That young man, once he received good care, has changed right around and wants to speak to everybody and explain the difference.

---

Then you have a few other subgroups. I think that depression, pathological depression, is a very important reason why a person prefers death over life. And that is treatable in many, many patients, yet it is not even mentioned. There is a little bit of research in that area. I do not know whether that is helpful or not, but I would be prepared to explain ...

**Mr POOLE:** Chris, I am very conscious that we are about 45 minutes over time. I do not want to limit you at all, but if you want to go through the rest of the bill, I wonder if you can just do quick summaries.

**Dr WAKE:** I think that is entirely appropriate. We will actually write all this up and post it in to you afterwards.

**MR POOLE:** I am conscious of the fact that we have other people sitting waiting to talk to us.

**Dr HOWARD:** I was going to comment on paragraphs (i) to (k), which are concerned with issues of competence and whether or not decisions are voluntary. What disturbs me most about these is that they fail to convey any sense of awareness of the complexity of deciding on both of those issues. The question of competence is acknowledged as one of the most difficult decisions a doctor has to make. Normally, if we are required to make decisions on competence, it requires at least 2 doctors of specified seniority. You are then required to appear before a magistrate to justify your decision. The magistrate then decides whether or not you have justified your decision.

In this instance, the bill presumes that a doctor will produce the wisdom of Job from nowhere, and be able to make a decision on competence in what is probably the most difficult situation in which to make any decision on competence, where both the doctor and patient are mentally and emotionally distressed by the subject of dying.

The question of the interaction of mental competence with depression has already been raised. I will not labour the point except to say that depression is invariably present to some extent and distorts judgment and decisionmaking. This bill does not offer any guidelines as to whether or not we should exclude depression before we assess a patient's competence, or whether we should treat depression before assessing competence. Similarly, it does not specify to what extent minor dementia should be considered in assessing competence.

It blindly ignores the complexities and subtleties of whether or not people make involuntary decisions. The pressures in this situation are not usually someone standing behind the patient, twisting their arm or pointing a shotgun at their head telling them to sign. The pressures are very subtle. There are all sorts of emotional pressures on people in this situation. People fear becoming dependent and feel an obligation to avoid that if possible. Patients may often fear that they lack the resources in terms of friends or family who can care for them. They may feel that they lack financial resources to provide the comforts. They may, in fact, lack emotional resources to face the battle ahead. All these patients are not really making voluntary decisions.

---

The worst possible subtle pressure arises when the patient feels that they themselves are going to become a burden and stress in a family situation or, worse still, where the family turns around and make it quite clear to the patient concerned that they are a burden and that it will be a jolly good thing if they disappear. The aged are particularly vulnerable to these sorts of pressures. The bill offers no guidelines as to how one should assess whether or not the decision is voluntary.

**Dr WAKE:** Mr Chairman, may I quickly summarise from here, rather than going on as we have been? Paragraph (n) implies that the judgment of competence can occur at a time remote from the act of euthanasia. We believe that, if there is any significant time gap and the doctor does feel the need to reassure himself, then it should indeed be noted at that time or reconsented and renoted that the patient remains competent.

**Mr POOLE:** We have actually identified that particular area. We did not really see somebody putting the request in and getting the certificate completed and then doing the job 6 months later.

**Dr WAKE:** We find paragraph (n) a little bit distasteful. I do not think there is any more to say about that.

**Prof. LICKISS:** It is terrible for junior staff, awful.

**Dr WAKE:** As for the right to rescind a request, the Dutch experience has shown that rescinding the request does not always mean that you do not get euthanased. I think it needs to be in the bill that the decision will be honoured. The bill says that the piece of paper will be torn up but, as I say, our concern is time and familiarity with this legislation and making sure that bad things do not happen.

Improper conduct is extraordinarily hard to judge and is perhaps the reason why other legislatures have decided not to legalise this. How do you judge motivation on the part of the person who does this thing? How do you accurately judge whether or not a person is competent to consent to have their life taken? These are huge questions.

In relation to records and reporting of death, we believe that this whole area should be subject to a strict audit. We would require to know the conditions for which this was done and the timeframe in which it was to be done. We think there are multiple things that the community has the right to know about, if this bill becomes an act. Certainly, the AMA would request that consideration be given to strict auditing practice.

**Dr LIM:** Do you mean an audit before or after the fact? I am not asking this facetiously. If you do it before euthanasing a patient, it might take several months to complete.

**Dr WAKE:** We were thinking that the audit would occur at the end of year, so that the community can know under what conditions and under what circumstances this legislation is being utilised. We think that is extremely important. If we have such an act, we do not believe that we should resile from it and run away from it. We want to know that it is working, God forbid, in a fashion that it is supposed to be working.

Under clause 4, this simple act seeks to cross over the common law, the NT Criminal Code, wills, probate, and so many of the essences of Australian law. Beyond that, it will negate the rights of the Medical Board in the Northern Territory and the Royal Colleges to have a say in how doctors should perform. We feel that this belies the simplicity of this bill. In our opinion, the bill seeks to justify what is not justifiable. In so doing, it crosses over the very essence if I can use that word of Australian common law, which is that life should be protected under all circumstances.

I have a final short statement in summary, Mr Chairman. We hope that we have given the committee some insight into our views of what does and does not constitute euthanasia in current medical practice. We believe that euthanasia is a rare and aberrant piece of behaviour. We believe it should be subject to the law.

We have shown or indicated to you that the Natural Death Act in the Territory is an excellent piece of legislation which really does equip doctors to react ethically to all death situations. That is not to say that palliative care is a panacea. It clearly is not. But we must bear in mind that suffering is an extremely individual thing and much more complex than just pain.

We believe that the bill has numerous and manifest inadequacies and we have been through those at some length. We believe that this legislation does indeed represent a very fundamental shift in the doctor/patient relationship. We want to go to work each day knowing that we are going to nurture and care for people and that they will be able to trust us to take care of their life, as indeed they have done for centuries. We reject the idea of a quick fix as being an appropriate way to proceed under any circumstances. Thank you, Mr Chairman.

**Mr POOLE:** Thank you.

**Dr WAKE:** While we have Prof. Lickiss here, are there any final questions that you would like to ask of her?

**Prof. LICKISS:** I have some really genuine comments to make. Of all the doctors here, I am about to join the ranks of the patients. I will have stopped doctoring by the year 2000, so I am very interested in what happens to patients. I do not say that facetiously. As I thought about this, I wondered what positive things could come out of it.

I think that it is possible for all of us in this room to agree profoundly on some things. I did list them and I made some copies. I am not really a paper person but I did make some copies. Really, there are some things on which we can all agree, and it should be almost a charter for the Northern Territory.

Firstly, every person is of value. Every person should feel valued, even the most powerless people. Every person should have basic medical care of the highest quality, and equality of access. It says all those things and you can read it.

Each person who gets cancer ought to have the chance of a cure or control of the cancer. That is self-evident, but it costs money, and you know that from a government point of view.

Every person with cancer should have their symptoms relieved, with palliation. That has been an issue in Indonesia. I have been trying to get the Indonesians to agree to have a little bit of morphine in the country. They do not have it at the moment. The vast majority of people who die of cancer in Indonesia do not have any analgesia etc.

Everyone in Australian society should have a chance for symptom relief. No general practitioner or hospital specialist should be left to face the difficult palliation problem without help, and neither should a nurse. No one should be stuck with no one to ring and no one to share the problem with. This is just wrong. It even applies to an isolated station. I have helped a doctor in Broken Hill through the last hours of somebody's life. About every hour, we talked on the phone. It is like remote control for the landing of an aircraft.

Every person with serious disease, whether or not it is curable or controllable, should have care. No one should feel that he or she should ought to die because there is no one to care for him or her. That should not happen in Australia today.

Every person will eventually die, and there usually comes a stage when futile treatments should be stopped and death be given a chance in the context of good care. That is terribly elementary, but I just thought that at least one can write out things that the people should be able to pin on their kitchen wall.

Each one of those steps implies practical, political action.

At 6am, I thought to myself: 'Now, what do I really think?' I have about 5 hats. As a palliative care doctor, I would not accept that euthanasia has a place in palliative care. I know that I have the world with me on that, except Adelaide. I love Adelaide.

As a cancer specialist and a paidup member of the medical oncology group, I know that one of the reasons I am able to be here is that 2 professors of cancer medicine are helping look after things. On the whole, cancer doctors find it aberrant that the idea of euthanasia would be seen as part of cancer practice. That is my 2nd hat. I have the support of my colleagues and their blessing to come up here.

Thirdly, as an ordinary doctor and I have been battling with this for a long time I find it aberrant. Anyone who thinks there is no difference between letting somebody die and doing the best you can, and going over that big river to the Dutch practice, just has not stood where I have stood for 30 years. I just will not have it. There is a profound difference. As a doctor, it is my conviction that the bill, though it is simple, distorts medical practice profoundly. I find that bill quite unacceptable. Frankly, I really find it unbelievable. I just have to say that. So you have heard it. As a doctor, I think that we doctors have to be the boundary. We have to sometimes be a wall against which society presses and pushes. It hurts, but somebody has got to make a stand. If it is not the doctors, who will it be? I do not know.

Fourthly, as an ageing person who has had 2 personal brushes with death, I want the community and the doctors to be in solidarity. I want no divisions and I want no curtains between people, and no lack of trust. I am an idealist, but I have realism and I have to live and work very hard at the coalface. I have to see the worst things that my colleagues at Prince Alfred can serve up, and try to help them. I know failure as well as success. Gosh, you have stopped dreaming at my age.

As an ageing person, I want the community and the doctors I can trust. I want the opportunity to exercise my autonomy. I would be the most dreadfully autonomous person in this room, and I want it. I also eventually want the courage to exercise what I think is the highest level in my autonomy, and that is to trust somebody to look after me when I have become vulnerable, to look after my dignity, to respect my wishes, and to care for me. That is going to be the hardest thing I will ever have to do, to eventually hand over autonomy. It is the highest exercise of autonomy to finally trust somebody. I want to trust them so that they can care for me.

My 5th role is as a carer, for heaven's sake. I have people I love and I care for. As a carer, I want to have everybody in solidarity. I do not want to have 2 doctors coming in and signing pieces of paper that I as wife, husband, lover, partner, child or whatever have nothing to do with. That is not giving solidarity to the care system, not at all.

I have my 6th hat and Paul Keating, John Howard and all the rest would be proud of me as an Australian. I do not want to have to be ashamed of my community because, at the end of 20th century in one of the best health systems in the world, the only way we can care for people is to terminate their lives.

I have been to Indonesia several times and I have lobbied with the head of drug regulation. I have never had people in Sydney listen to me like this.

**Mr POOLE**: They probably did not get paid for it.

**Prof. LICKISS**: I have been in Indonesia several times, pleading with the drug regulator and we are now good friends that to give a little bit of morphine to people with extensive cancer will not turn them into addicts and will not wreck society. At this point, I would like to say something to you in confidence.

**MATERIAL PRESENTED IN CONFIDENCE**

**Dr WAKE**: Mr Chairman and members, thank you very much for your patience.

**Mr POOLE**: Thank you.

**CONFIDENTIAL**

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 16.35 pm

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Ms Penelope Campton

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 16.57 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr Rodney Syme

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

1

---

**Mr POOLE:** I am sorry to delay the proceedings, but we are trying to ensure that people who appear in front of the committee have the opportunity to say what they want to say without having to walk away feeling they did not get heard.

I welcome you, doctor, for appearing today to give evidence. Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful.

I also advise that the committee has authorised for the purposes of this inquiry that the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Please advise us now if that is the case.

**Dr SYME:** I am happy for it to be an open hearing, sir.

**Mr POOLE:** Thank you. For the Hansard record, please state your full name and the capacity in which you appear today.

**Dr SYME:** Rodney Robin Adlington Syme. I am a medical practitioner specialising in urology.

**Mr POOLE:** Thank you, doctor. Do you wish to speak to your submission? Then we can go into a general questionandanswer session.

**Dr SYME:** Yes, I would like to do that. In the submission, I have made a number of comments. I would like to, at this oral opportunity, develop some issues.

I believe there are 3 principles which doctors follow. Those are that we aim to save, preserve and prolong life, that we relieve suffering, and that we respect the rights of our patients. As we move towards the end of life, all doctors, I think, would recognise that it is the quality of life and not the quantity that is important. Therefore questions of saving, preserving and prolonging life become less important. When we are talking about the terminally ill, we are no longer talking about saving life. This is incurable disease. We are then left fundamentally dealing with 2 principles, of relieving suffering and of respecting the patient's wishes.

If I have a patient who tells me that their suffering has reached a point where it is no longer tolerable to them, in terms of the treatment that I am giving them or they are capable of having, and they request my assistance to help them to relieve that suffering, then I believe that applying those 2 principles, I have a responsibility to that patient to assist them. Many doctors find this difficult, because they cannot divorce from those principles their own religious morality, which would say to them that it is wrong to do that. But that is an intrusion of their religious morality into the fundamental principles of medical practice.

2

---

In the practice of medicine today, I believe there is a considerable element of hypocrisy. Doctors assist patients to die today, they have been doing it for generations, and they will continue to do it whether this legislation is passed or not. Doctors in the vast majority are compassionate human beings, and we do assist patients to die. The hypocrisy is that it is not talked about, and it is carried out in a variety of different circumstances and it is an occult event.

Many of the processes that are carried out are undoubtedly processes whereby the patient's life is ended. If you have listened to the members of the AMA, they almost all admitted that they had assisted in the death of patients. Because of the law which exists, the process of assisting a patient to die in many cases is one which could only be described, in my view, as a slow euthanasia. If a patient is in extreme suffering, it is thought of as good medical practice to treat that patient with sedation and analgesics.

` There is no doubt, at the point at which that process starts, that death is the only outcome. For the doctors to remain within the law and to remain within their conscience, they are forced to say that that is an action of double effect. This ignores the patient. It is a comfortable process for the doctor to engage in a process of slow euthanasia or pharmacological oblivion, but it ignores what the patient might desire. Respect for the patient's opinion is simply not observed. Rather than have a process which might last 7, or as we heard earlier this afternoon, a process which lasted 12 days, the patient might have an opinion which stated they would like the process to be rather quicker.

I personally would not regard as dignified a process where I treated a patient and put them into a state of coma for 7 or more days. I do not regard that as a dignified process. It is a process of medical futility, and you heard Professor Lickiss say that we should not be involved as doctors in processes of medical futility. She acknowledges that the patients had a right to determine what treatment they would have. Yet, by the same token, she pleads that they will not have a right to have their lives shortened in a quick way rather than a prolonged way.

The process of voluntary euthanasia was characterised by the representatives of the AMA, time and time and time again, as a quick fix. Now, that is an emotive phrase which is just totally unrepresentative of the process of voluntary euthanasia. I use the word 'process' because voluntary euthanasia is a process, not an event. A quick fix is an event, and that raises the idea of a doctor being approached by a patient, asked for euthanasia and the doctor says: 'Right, pop up onto the couch there. I've got a syringe all ready for you. Let's go to it'.

Those of you who saw the Dutch documentary shown on Channel 8, Death on Request, would have seen the process by which a patient and his wife and the doctor moved steadily, and through discussion, ultimately to voluntary euthanasia. That is the way that voluntary euthanasia ought to be practised. It is a journey that is undertaken by the doctor and his patient. It involves counselling and discussion. It involves the doctor, under the terms of this bill, being absolutely sure that that patient is of sound mind, being absolutely sure that that patient is not under any duress.

3

---

I have assisted patients to die. When a patient comes to me and asks to be helped to die, the first question that enters my mind is: What is the mental state of this patient? I am seeking for evidence of depression or unsound mind. It stands to reason that anybody who asks you that question is asking a very extraordinary question: The first thing you must do is establish whether the patient is of sound mind or not. Are they suffering from depression? Have they a treatable condition?

A patient is never persuaded by a doctor that they should undergo euthanasia. The process is the reverse. The doctor has to be persuaded by the patient that the conditions are appropriate. You need a synchrony of mind between the patient, in his suffering, and the doctor who sees it as appropriate.

The guidelines that are in this bill are specifically designed to place a responsibility on the doctor. The same responsibility, to my mind, should be placed on the second doctor. There is a specific responsibility on that doctor to ensure that that patient is of sound mind.

Now, it is said that doctors will overlook the concept of depression. They overlook it when they are not looking for it. This doctor is given a specific task to determine that that patient is of sound mind. If you are seeking for depression, it is not difficult to find. If you have the slightest doubt that it is there, of course one would insist on treatment or a second opinion.

Item 9 in a recent position statement of the Australian Association for Hospice and Palliative Care Inc. 'recognises and respects the fact that some people rationally and consistently request voluntary active euthanasia'. It is not a concept that it is outrageous to suggest that patients who request voluntary euthanasia cannot be of rational mind. In my view, it is not a question of if this legislation should be passed, but how it should be designed so that it is safe.

We turn to the question of palliative care, which has been given great emphasis. I am personally a great advocate of palliative care. At the same time, I am an advocate of the patient's right to determine the outcome at the end of their life. I see palliative care and voluntary euthanasia essentially as complementary not in opposition to each other. A patient should have a right, going through palliative care, to reach a point where they say: 'My suffering is not being adequately relieved. I want out. I want something else'. It is not for the palliative care doctors to say to them: 'We're sorry, but we're doing the best we can. You'll just have to put up with it'.

Palliative care, it is acknowledged, does not relieve all the pain and suffering of the terminally ill. I refer you to item 10 of this document. It acknowledges that 'while pain and symptoms can be addressed, complete relief is not always possible in all cases even with optimal palliative care'. The figure has been put somewhere between 5% and 10% of patients, asking for palliative care and receiving palliative care, in whom the optimal aim is not achieved. I do not for the life of me see why these people should be sacrificed to continued suffering when they do not request it.

Secondly, there are conditions which do not even come within the bounds of palliative care. How do you palliate the suffering of a person with motor neurone disease, or multiple sclerosis, or AIDS? The vast majority of people with AIDS do not have palliatable symptoms. I could list a whole heap of other conditions which are frankly almost impossible to palliate. That does not even take into account the psychological impact of suffering on many of these people.

The very important corollary, I think, that I would impress upon this committee is that as a consequence of this bill being passed, if it is to be passed, the government of the Northern Territory has a very, very heavy responsibility to ensure that appropriate guidelines are drawn up by the medical profession to advise on the proper practice and that funds should be dedicated to a proper and appropriate education process for the medical practitioners in the Territory, very few of whom will have had any experience of palliative care. It would be wrong to pass a bill of this sort and not to undertake an appropriate educative process for the medical profession, so that they have an understanding of the ethics and practice of palliative care, because it is foreign to the vast majority of doctors practising.

I thought the AMA's discussion of the bill was a very bad example of special pleading. It could be taken that many of the criticisms they raised would be criticisms of almost any piece of legislation that could be drawn up. If you look at a bill, perhaps, which says that murder is a crime, people would say: 'Well, that bill doesn't stop murder'. They are saying about this bill: 'You can't pass this bill, because it might be abused.' Do we not have a bill about murder because it might be abused? It is nonsense. You cannot have any legislation passed which is not capable of being abused. The fact is you do not not pass that legislation, you do it in the best possible manner, so that abuse is kept to the absolute minimum and where abuse occurs, it is seen and dealt with.

A few quick items relate to the question of a patient who had attained the age of 18 years. The AMA stated that this was ridiculous, because you could have minors who would be capable of making their own decision. I imagine if the bill had not said that the patient had attained the 18 years, they would have said: 'This is an awful bill because you're allowing minors to be involved in this conduct'. Whichever way you put it, I am sure they would have complained.

Similarly, with item (b), the term 'terminal illness' is not a definable term. Any medical practitioner can tell you that. It is a state which is recognised by doctors, and you cannot define it in legislation. Again, the question of 12 months if it had been 6 months, they would have complained that that was too short or too long. The fixing of a time in this bill, I think, is a contentious matter. In my view, it is simply there as a signal to make it clear to the doctors and the people that this is a bill which applies to people who are terminally ill. The longer the period of the terminal illness, the greater is the suffering that the patient is open to. We have advised, in the bill which my society has drawn up, that 12 months is an appropriate time because people with motor neurone disease and multiple sclerosis can be suffering for at least that length of time in the most appalling conditions, and to exclude them from the terms of this bill would be totally inappropriate.

---

Under item (f), Professor Lickiss took exception to the word 'acceptable' whereas, in her presentation of her case earlier, she said that she was fully agreeable to accepting the patient's own determination of what was acceptable treatment. Her patient decided that they would not have investigations or treatment for possible septicemia [inaudible]. That was what the patient found acceptable, and in that instance she accepted that that was appropriate. When similar phraseology is included in the bill, she suddenly takes exception to it.

Under (k) there is indication that the patient must be found to be competent. This is a decision that doctors take every day, every time a patient consents to some procedure or another. Medical practitioners determine whether that patient is competent or not. When I obtain a patient's consent to an operation, I have to take into account whether the patient fully comprehends what I am telling them with regard to this operation. The idea that you have to have a panel of people to determine consent or, as the doctor here said, you have to go to the bench to determine whether appropriate consent has been made, is, I find, totally stupid.

The next point there is the phrase 'after due consideration'. That phrase could perhaps be developed into something like 'an enduring request'. It is not the intention, I believe, that a patient would be able to come in, under the terms of this bill, ask for euthanasia and have an agreement done there and then, on the spot. It would require an enduring request. As this states, 'due consideration' means an enduring request that is, one which is repeated in time to ensure that the request is persistent, genuine and firmly held.

Complaint was made about the fact that there was no audit. I would see that under the bill, section 12(2), where the death certificate has to be annotated as to the fact that the process has taken place under this bill, that that is then advised to the Coroner, the Coroner shall advise to the Attorney-General and on to the parliament, so that the report is issued to ensure that the public is aware totally of the practices that have taken place under this bill.

When I was coming up in the aeroplane yesterday, I was reading my Australian and I saw this headline: 'Exploitation of Fear is Criminal'. This is by Hugh McKay, a noted social writer. I wondered if he was talking about euthanasia, but he was not. He was talking about the behaviour of the parties in the recent New South Wales election, where they were using fear of the possible explosion of crime in the state to exploit the community, the electorate. Now, I have to say that to some extent I find the activities of the opponents of this bill to border closely under that heading.

The fundamental argument that is put against this bill is that it is against morality. It is a moral issue, but the point should be made that your morals and my morals are each an individual matter. We do not all function under one moral view. Therefore, an argument which states, 'It is my moral view that this bill is immoral, and therefore should not be passed', is inappropriate. It is not the place of legislation to support the moral views of one section of the community. That argument about morality is not a fundamental argument of this debate. To argue that I think it is immoral, and therefore the bill should not be passed, is to say that I have the right to impose my morality on other people. That is not a tenable argument.

---

Once that argument is found to be untenable, the major argument that comes out, in my view, is one of trying to create a situation of fear that all manner of appalling things will happen in the community if this legislation is passed. You saw examples of it this afternoon, where material which was completely beyond the scope of the bill was used, and raised as issues when the activities that we saw in these cases are simply excluded by the bill. The bill quite clearly allows only for voluntary suicide or euthanasia and the attempt is made in discussing this bill to try and create a situation of fear that something other than that very restricted possibility could occur. Thank you.

**Dr LIM**: Using your last statement, about fear, your argument says that the slippery slope does not exist, and that this bill will not allow for an expansion of the demands or the less exact policing of the act. Therefore there should be no more euthanasia cases, other than the very restricted ones that we talked about.

**Dr SYME:** That is what the bill states, does it not?

**Mr LIM:** Yes, it is what the bill states. But look at other legislation a 60 km/h speed limit, for example. We drive at 65, 70 km/h. Lots of police ignore that, because that is the roundingoff of legislation. To be exact is onerous on the police as well as on a citizen. In fact, any legislation that is enacted tends to be rounded off by the legislators, by the enforcers and by the citizenry. So do you think the slippery slope could occur with this bill?

**Dr SYME:** You have to have a patient who puts his signature to a piece of paper. You do not have to do that when you are speeding, with respect.

**Dr LIM:** But you are speeding because you want to do it. And if the patient wants to have euthanasia ...

**Dr SYME:** That is right, the patient does, and under the bill the patient would be allowed to. If you equate that with speeding, the patient would be allowed to have euthanasia. But as far as abuse is concerned, nothing can happen under this act unless the patient attests quite specifically that they want it to happen. I believe that a second safeguard should come into this bill, and that is at the time of action, when either the patient takes his or her own life or voluntary euthanasia is administered, that a second signature ought to be provided to make a final affirmation that that is what the patient wants.

**Mr POOLE:** And one, presumably, that could also attest to the patient's competency at that time.

**Dr SYME:** The whole process of competency, of duress, a revision of all the provisions of the bill, ought to take place at that time.

**Mr POOLE:** In your paper, doctor, basically you are saying that the debate really should not be about whether voluntary euthanasia should legally be allowed, primarily because, as you attest, it is already happening in our society. What should be examined are the safeguards within the narrow confines of the bill, to make sure that the law is strictly adhered to once the bill is passed. That is your primary concern?

**Dr SYME:** That is right. We have a hypocrisy at the moment. Euthanasia is being practiced described in a whole lot of terms other than that and it is being carried out under conditions that the medical profession seems to think are appropriate, in accordance with their wishes and their deliberations. It is not being carried out in accordance with what the patient would want. That is to say, the medical profession and the AMA say: 'Yes, we can assist you to die, but it's on our terms, and it will be slow' As we saw here, it took 12 days on one occasion for that patient to die. I do not know about you, sir, but I certainly would not opt to put my hand up for a dying process that took 12 days.

One of the fundamental reasons why I became involved in this debate is that I have seen things happen to patients which I, as a doctor, would simply not allow to happen to myself. As a doctor, I have the knowledge of medical processes, of pathology and disease. I have the means, because I can get hold of the drugs any time I like. I have pondered this ethical question: If I am faced with a certain condition which is causing me absolutely severe distress and pain and I decide, as a doctor, that that is the point at which I do not wish to go any further through this dying process, I can opt out, I can take my own life. If I can do that for myself, how can I not say that that should be available for my patient? For me to say, 'It's all right for me but tough, Jack, it's not for you', I find absolutely morally reprehensible.

**Mr STIRLING:** Nonetheless, you did say in your last page that it is our task as legislators to provide the legal framework to make it safe, in so far as that is ever possible, which suggests that you have some doubt about locking it up beyond all doubt.

**Dr SYME:** Any legislation that you make, a person can break. That is not an argument for saying you should not do it, because it can be abused we would not write any laws. When you open a casino here, you recognise the fact that abuse could take place, that you could get profiteering and criminals. So you write legislation and you run the casino in a way that is going to be honest, fair, above board. It still does not make it impossible for somebody to do something wrong. As legislators, it is your task to see that it is done appropriately and properly and carefully and safely. Beyond that, you cannot do more. But to say, 'We'll open a casino. We'll have no legislation because somebody might break it' that is a farcical idea.

**Mr POOLE:** You say that it is happening now, euthanasia is being practised. I acknowledge that we have had some evidence given to us that would indicate that. Then it comes down, I guess, to the intent of a person when they administer the drugs. Is it purely to relieve the patient's suffering, or is it to actually terminate their life? Do you think it is a very common practice in Australia?

**Dr SYME:** It depends how you define it, of course. If you look at the debate as it has gone on over the last 20 to 30 years, there are things done now which would have been regarded as euthanasia 30 years ago. We agonised over things like turning off respirators people thought that would be an act of euthanasia and withdrawal of treatment. All of these things have been gradually dealt with by society and the medical profession, so they are no longer called euthanasia.

We are down now to a very narrow spectrum of what people call euthanasia. But in my view, the practices of a lot of palliative care, when you get to a patient whose suffering is so gross and extreme that you take a decision to use drugs that will have only one outcome, and that is the death of the patient, that is de facto a form of slow euthanasia. I can tell you that in many cases that is nonvoluntary. The medical profession, the AMA, choose not to call that euthanasia. They choose to call it good medical practice. But I cannot for the life of me see what is the difference between a process like that, which takes 12 days, and the outcome is absolutely certain, and a process which takes 1 day with the patient's consent.

The argument is about intent. Who knows what intent is? I can say what my intent is, but nobody can prove what it is. A person of strong religious persuasion might very well say: 'I am just treating the suffering, I don't intend the death of the patient'. If you are more of a realist, you might well say: 'I'm going to relieve the suffering, but I realise that in relieving that suffering there's only one outcome, and that's death'. How can I not intend the one and also the other?

I would put it to you that I, as an advocate of voluntary euthanasia, would say that when I am assisting a person with voluntary euthanasia, my primary intention is to relieve the suffering. My primary intention is not to kill the patient. But there is an indivisibility between the 2 actions. There is some suffering that essentially can only be relieved by the death of the patient. Therefore, to say what the intent is to split the infinitive, almost is just impossible. For me to say that when I practice voluntary euthanasia my intent is only to relieve the suffering, is to be ,I believe, a little bit hypocritical and dishonest. I must recognise the reality, that the only outcome is that the patient will die. But the primary basis for taking that action is the relief of suffering.

It is just a matter of slight emphasis. People of certain moral persuasion would see that that is an important emphasis. Norelle Lickiss calls it a very fine line. She can see that fine line in her own mind, in her own moral concept. To me, coming at it from a different moral perspective, I do not see that line as being there.

**Dr LIM:** Talking about moral perspectives and moral views, the whole Australian ethic is based on the JudaeoChristian ethic, granted that some people claim that there are 82% Christians in Australia, versus some others who say there are only 21%, and therefore there is decreasing Christianity in this country. Be that as it may, if there was not a single declared Christian in Australia, the ethic remains Christian because all our laws, all our beliefs, are based on the Westminster system, which is based on the Judaeo-Christian system. So if you throw that morality argument out all together, you are throwing away not only the 200 years of modern Australian history, plus the rest of the British history that we inherited, but essentially you are saying to the western world the United States, Canada, Britain, the British Commonwealth and Australia forget about morality because that Christian morality is irrelevant. How do you rationalise that?

**Dr SYME:** There is an equal morality which would say that it is totally wrong to allow people to suffer torture. I believe that would be part of the morality, that we do not

allow torture. I would remind you of the definition of 'torture' in your dictionary, and that is to inflict physical or mental suffering. There is no doubt that some people when they are dying have mental and physical suffering inflicted upon them in our Judaeo-Christian society. There are a lot of people, Christians of all denominations, who have spoken to me, who have written to me I have had senior people in various churches write to me in support a very large body of opinion, and you have seen the figures of the public, whether 68% of them profess a faith or not, there is a very, very, very large body of opinion in this JudaeoChristianbased country that this bill ought to be passed, and that heaven and earth will not fall down if it is done. They believe it will be a fairer and better society for this bill being passed.

I will tell you, if this bill is not passed in the Northern Territory quickly, it will be overcome by a rush of bills in other countries. You have a chance to go down in history, gentlemen, as having made a very, very important piece of humanitarian social history. You also have the opportunity to go down as a group who missed an opportunity to do something for democratic society.

**Mr POOLE:** I should say something facetious about courageous decisions that politicians make, but I shall not.

**Dr LIM:** The Hobbes principle is that if it comes down to the very bottom line it is about survival, and therefore about life. I value my life just like you value your life. If I value my life slightly less, then I will, in fact, value your life even less than mine. You do not agree with that?

**Dr SYME:** I do not agree with that at all.

**Dr LIM:** Taking it down to the absolute bottom line, if my life is more important than yours, that I should value your life less than mine?

**Dr SYME:** It depends entirely on the circumstances in which you are valuing it. If I am a fit, healthy person and you are suffering absolute misery, then you might well place less value on your life than on mine. I do not think, because of your situation, you would devalue my life. I do not believe in absolutes, Dr Lim. They do not make for rational argument.

**Dr LIM:** We do physics always on absolutes, do we not? Take an example of you and I both starving for 10 days in a jungle. We stumble on a fruit. If we eat that we will survive, at least for several hours to several days before the next fruit, if we find one. I would value your life less than mine, because we are both now struggling to survive. This is the last fruit. If either you or I eat it, one of us will survive or we could share it. If I do not value my life very much, I value your life less. Similarly you value my life less than yours. It is either I kill you or you kill me first, before we eat that fruit. That is the bottom line.

**Dr SYME:** No, your argument is wrong. If that is the only fruit, if you eat it, you are going to die, too just a little bit later than me.

**Mr POOLE:** I was going to say, is this a Chinese riddle?

---

**Dr LIM:** Maybe I am not getting my argument across properly. That is all right, we will leave it at that.

**Dr SYME:** I bend to the philosophy of John Stuart Mill rather than Hobbes.

**Mr POOLE:** More questions? Well, thank you very much for appearing in front of us. Very interesting.

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 17.47 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representatives:

Mr Wayne Wood

Mrs Rosemary Wood

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** I welcome the following witnesses and apologise again for keeping you waiting so long. Mr Wayne Wood and Mrs Rosemary Wood are appearing to give evidence.

Other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information you give to this committee must be truthful.

I also advise that the committee has authorised for the purposes of this inquiry that the usual proscription on the disclosure or publication of material placed before the committee by witnesses need not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Please advise us now if that is the case.

**Mr WOOD:** We are happy to speak in public.

**Mr POOLE:** Thank you. For the Hansard record, please state your full names and the capacity in which you appear today.

**Mr WOOD:** Wayne Kingsley Wood, private citizen.

**Mrs WOOD:** Rosemary Helen Wood, the same.

**Mr POOLE:** Welcome. I am sorry to keep you waiting so long. Please feel relaxed, we can do this quite informally. You say what you want to say, and if we have questions we will ask you some questions.

**Mr WOOD:** I have typed out a submission. I am going to talk to it. I shall be happy to answer questions afterwards, and will give you a copy of the submission. Unfortunately I did not do it early enough for you to have it in front of you. I shall speak only to the bits that are particularly relevant to our discussions this afternoon.

We do not have a pro case or a con case. Basically we are just here as private citizens who, because of particular circumstances, feel that we have something to offer the committee in its deliberations. Just as a preamble, in 1992 our 15yearold son was diagnosed as suffering from Ewing's[?] sarcoma, which is an aggressive form of bone cancer. Most of 1993 was spent travelling to and from Adelaide and at the Queen Elizabeth Hospital, where David received the best care currently available. Unfortunately the cancer was not cured and on 6 January 1994 the oncologist informed us that David had approximately 6 to 10 weeks to live. The cancer, originally confined to his rib, had invaded his lung, spine, hip and femur.

The decision to care for David at home occurred by default. There was nothing that more traditional medicine could do, and we would try to care for David in our own way, somewhere both we and David felt comfortable at home. The reason for this is that hospitals are institutions that have to reduce everything to a routine in order to be able to cope with emergencies which may result in death or worse, litigation.

---

Thus the terminal patient threatens the hospital and its sense of routine. The rules, the predictable activities for instance, waking the patients to take a sleeping tablet cease to be meaningful and cease to be effective. The hospital and its personnel tend to reward the dying patient for maintaining the denial phase, because it protects the staff from becoming involved and facing their own feelings. Hospitals are not designed to absorb or cope with anger. Patients are encouraged to feel dependent on the medical staff, made to feel grateful for the care they receive, and feel guilty if they upset routine and order. Therefore the patient who expresses anger does not only communicate a personal need, not only a cry for help, but indeed violates the routine, the rules, the order, and so threatens the institutional systems.

Part of the problem of caring for the terminally ill patient at home is that anyone who is committed to recovery, to healing, cannot avoid the sense of failure when the patient dies. You cannot help wondering whether every possible thing had been done, whether other kinds of resources could have been invoked, whether all the diagnostic and therapeutic means have been employed. You ask the question, is there someone, somewhere, who has the new knowledge that could have made the difference? By the time David came home in January, he was too sick to leave home. Therefore the idea of travelling to Mexico or the Philippines for faith healing was never discussed not that any of us was predisposed to try any of that rubbish anyway.

Death devoured him, it scoured the flesh from his bones. I cannot read this bit. You will have to read it. David always was very, very dignified ...

**Mr POOLE:** Take your time.

**Mr WOOD:** David died on 6 August, 7 months to the day he was given just weeks to live. Luckily it was a peaceful death. We were not required to face the momentous decision on whether or not I had the courage to assist him.

I see a dilemma in this proposed legislation. As the Chief Minister said in the second reading of the bill, the problem for patients who wish to end their lives is that they cannot be assured of finding a sympathetic doctor. The rights of the competent patient should be absolute. These rights, summarised by John Stuart Mill, referred to in the AMA submission and by Dr Syme previously, and also quoted by the Chief Minister, indicate to me that it does not matter what the doctor believes. Whether or not it is offensive to the doctor's understanding of his legal or ethical situation, the patient should be able to exercise the most basic right of all: to live or to die.

'When is enough enough? When has one the right to ask for relief from unbearable suffering, when all means have failed and life no longer has any quality? Physical pain can usually be relieved by palliative means, but the psychological pain and depression associated with the loss of ability to function, to be totally dependent on others for even the most essential and common toiletries, even to blow one's nose, is dehumanising. Some people have the spiritual fortitude to cope with this dependence, but for many it is a burden too hard to carry'. That is quoted out of the Australian Family Physician, June 1994.

---

My grandfather, who reaches 88 years of age this week and who is a deeply religious man, has written to me: 'I am a firm believer in euthanasia, especially after the death of Nanna and Gordon. [Gordon is my uncle, who also died of cancer.] You would never let an animal you love suffer like that. I can recall visiting Nanna during the last weeks of her stay in hospital. She used to hold my hand and say, "Daddy, why won't he let me die?" [I am still quoting from Pop.] I asked the doctor to terminate her life by leaving a tablet by the side of her bed, and I would give it to her. For Gordon to be kept alive for 6 months, the last 3 in a coma, was a sin against humanity'.

In our experience, the local GP has little interface with the terminally ill patient during the treatment phase. Oncology patients, for instance, are treated interstate by specialists, usually returning home only to die. The GP does not have the expertise to treat the latter stages of a disease like cancer. The days of the family GP having a detailed knowledge of the individual family members' general state of health, let alone their attitudes on sensitive subjects like euthanasia, are long gone.

Some 8 months after David's death, I asked the GP who wrote the narcotic prescriptions if, had we asked, he would have helped us ensure our son had a peaceful death. He responded unequivocally that he disagreed completely with the proposed bill and would not under any circumstances assist euthanasia. Thus we would have been beset by the most awful trauma of having to find another doctor to help us. In addition, we feel certain that had we mentioned the subject to the GP, he would have restricted the supply of morphine to the daily dose, instead of giving us 4 or 5 days' doses at once.

Another part of the problem is the district nurses who, although by far the most experienced in caring for the terminally ill, are subservient to the usually inexperienced GP. They would follow the dictates of the GP, even though they themselves may agree with the patient. I have now quoted from Nursing Management, October 1994: 'The nurse's duty is to care for the patient, to assume their wishes to have treatment. The ethic is to do good, the law to do what a reasonable nurse would do. Reasonable nurses generally care for patients until ordered to stop, either by the patients themselves or by persons authorised to speak to them'.

I have also referenced a position statement on the promotion of comfort and the relief of pain in dying patients in the American Nurse Journal, February 1992. To quote from the Territory AMA submission: 'Doctors are not educated in the matters of ethics, medico-legal medicine or the dying patient. The expertise or lack of it that they exhibit in these matters is entirely a result of their own level of interest, studies and life experience. And further, nurses have even less training than doctors in matters of ethics and the legal aspects of medicine and death'.

The summary conclusions of the British House of Lords select committee, listed in the same submission, recommended maintenance of the status quo. They include, inter alia, 'training of health care professionals should prepare them for ethical responsibilities' suggesting that not even the British system, which is held up by both the Territory AMA and the Right to Life sponsored Robin Bernhoft as the last word on the efficacy of palliative care, has all the answers when it comes to ordinary GPs being given the responsibility to decide the ethics of any particular case.

---

We completely agree with and support the call by the Territory AMA for an early review of services, with consideration of community hospice accommodation, employment of a specialist palliative care physician, and extension of the palliative care nurse system. There is a need to educate doctors and nurses about the medico-legal and ethical aspects of dying. However, we strongly disagree with the next sentence, that there would be no need for discussion of euthanasia, because even if the bill fails and we hope this is not the case this debate has been good for the community.

We finished with a suggestion for a solution. This may be presumptuous of us, but we figure we have been there and we have seen the system, and this is a short attempt to overcome what we see as the dilemma. In his letter to the Chief Minister, Brendan Nelson stated: 'Attempts to legislate the relationship between individual doctors and their patients creates an environment in which the patient and doctor see each other as potential adversaries, inevitably at the expense of the patient'. It seems to us that the easiest method of overcoming this, and many of the other criticisms made by both the AMA and Right to Life, is to amend the bill to remove the responsibility of dealing with the certificate of request from the untrained medical profession.

I suggest the establishment of a review tribunal consisting of three people: one with a legal ethics background, the second an experienced psychologist or psychiatrist, preferably with palliative care experience, the third a community representative patient advocate perhaps someone who has had the experience of a loved one dying a protracted death. The terminally ill patient initiates the request for assistance verbally and in writing, in the same way as they would under the proposed bill, to the tribunal, which investigates the circumstances, interviews the patient, the family, the medical practitioner and anybody else that they want to, to establish consent and competency, and only if unanimous in its decision, approves the request. If the current medical practitioner is uncomfortable about compliance with the request, the tribunal assists the patient in obtaining the services of, and transfer of the patient records to, another medical practitioner.

That is our submission. We would be happy to answer any questions.

**Mr POOLE:**.. I think it is all pretty forthright, what you have said. I guess we are all coloured by our personal experiences. One of the reasons for the change in the tenor of the debate was that the situation is becoming more common in our society as we talk about family experiences. 10 or 20 years ago nobody used to talk about things like that.

**Mr WOOD:** I think if anything is learned from this debate, it is that we do not talk about death and dying enough in this society. It is a taboo subject. Opportunities like this enable us to get out and talk about it. For me it is very cathartic and, you know, it is ... I know I have not performed extremely well, but people find it extremely difficult to talk about death. And they should not.

If only 2 or 3 people in a year come under the auspices of this bill, then that is sufficient reason for it, because those 2 or 3 people choose not to be tortured, either psychologically or

---

physically. As Dr Syme said and I believe, that is what it is. The doctors can go on talking about palliative care, but how do you diminish the psychological pain and anguish of a person who knows that they are going to die from emphysema or from multiple myeloma or from multiple sclerosis and last of all, cancer? That has been our only experience, but certainly I have seen situations where old persons know they are going to die. It seems to me only reasonable that they be given the dignity of choosing when they die. I always say, and I have been [inaudible] in this, I have a horror of not being able to wipe my bum. It seems to me that if you are going to have any dignity in life, then you should be able to choose the passing of it.

I think you can dismiss this slippery slope thing. This will only apply to very, very few people. If you make it tight enough, it may not apply to anybody in any given year, and there need not be any audit. I do not think there need be any fear by the medical profession that they will be called upon to put down people. But if it helps 1 person in any year, I think that person deserves the right to be able to say: 'I don't want to die a lingering death'.

It did not affect us. David was not 18. But I suspect that if the bill is successful, you will be approached or somebody will be approached by parents like us who say: 'If it's okay for a person over 18 to choose to die, why should a person under 18 have to suffer?' You were speaking earlier, Dr Lim, about extension of the legislation. I have no fears, but it will happen. You will be asked to change the legislation from time to time. But I think in a mature community where these things are debated widely and openly, there is no reason why that should be a fear.

**Mr POOLE:** My attitude towards the possible change of legislation is that we could change the whole thing here and now, and it could go through tomorrow. I guess the morality of our society at the time will dictate those sorts of things. Who, 25 years ago, would have thought that terminations would be allowed?

**Mr WOOD:** As Dr Syme said, 25 to 30 years ago pulling the plug on a respirator was considered euthanasia. I think we are a much more mature and open society now, and the very fact that we can debate things like this indicates to me that it is a healthy thing. If we keep pushing it away and saying, 'No, no, we cannot even talk about euthanasia', I think that is unhealthy.

**Mr POOLE:** Do you wish to add anything?

**Mrs WOOD:** No, nothing to add.

**Dr LIM:** Thank you for the stories from your life experience. Thank you for sharing that with us. With the general practitioner, had he not been able to cope with euthanasia at the end of it, this Dr, Professor ...

**Mrs WOOD:** He was not asked.

---

**Dr LIM:** No, I understand that. But as Prof. Lickiss said earlier, the fact that she does not believe in euthanasia does not mean that she would not walk with the patient, and actually ensure that the patient has a dignified, comfortable if not painfree, comfortable dying process. She would in fact go pretty well all the way, except for the act of euthanasia.

**Mrs WOOD:** But how long can you allow that process to go on, especially if the patient does not want to remain in that situation? This is the main argument, basically. We had a patient who was bedridden for 8 months. He could not move, could not even turn unless he was actually turned. He was still quite 'compos' mentally, but could do nothing and could see other people doing things. Very distressing.

**Mr WOOD:** Imagine the psychological trauma of a 16 year old boy. It never came up for us. That is why we do not have any axe to grind one way or the other.

**Mrs WOOD:** I think, too, that perhaps the reason it did not come up in his situation was that the life experience of someone that age is not there for them to even think about the possibility of asking. Perhaps that might be the reason, whereas a normal person ...

**Mr POOLE:** With the advent of bills like this, of course, maybe his situation would have changed in 10 years' time. He might have asked.

**Mrs WOOD:** It might have done, yes.

**Mr WOOD:** We sit in this room and in the community as parents, but I am sure that schoolchildren and teenagers and so on are reading the newspapers and understanding perhaps they do not understand the full depth of the debate, but they understand what is going on and ...

**Dr LIM:** They do school projects on it.

**Mr WOOD:** Yes, and it is not unreasonable to assume that at some stage in the future, someone is going to put their hand up and say: 'Why should that person be relieved from his pain and suffering because he's 2 months older than I am?'

**Mr POOLE:** I think, though also having 3 kids that there is a certain ring of truth about the immortality of kids of 14 or 15.

**Mrs WOOD:** I would agree with that.

**Mr POOLE:** While they might read the newspapers and listen to the debate today, they are not really thinking about the possibility.

**Mr WOOD:** They are all immortal as teenagers. But one thing about your child dying is that it does impress upon you your mortality. It brings home to you, in a way that is probably unequalled, that we are only here for a short time. It seems to me that if my time is up, I want some input into how I am going to go.

---

I am just reflecting on what you were saying earlier about the GP. One of the results of our experience I do not wish you to take this personally was the arrogance of the whole medical profession that we dealt with. They wanted to be in control of the whole process, right? Now, for us it was not such a major problem, because we developed a sort of handsoff relationship with the GP. He was very good, in that he practically did what we asked of him and nothing more. It was good in that respect. But I can see a situation where the GP would drive the process in the direction that he wanted, even though the patient was uncertain.

I would like to see some sort of legislation which perhaps removed the responsibility because that is a major concern, as I understand it from the doctors and nurses. They do not want to be placed in this situation.

I would like to see a bill which removes the patient and the family from a situation where they have to be supplicant to the doctor, giving them an outside method of arbitration. If we do not like the doctor and he will not do what we tell him, we can go to somebody else who will arbitrate it. That is why we had the presumption to say we would put up some sort of solution to the problem, which I think will overcome a lot of the difficulties associated with the AMA. They do not really want unqualified, untrained doctors placed in a situation where they have to make a decision which may be unacceptable to them.

**Mr STIRLING:** As a member of the committee I thank you both for coming in. I salute your courage in what you did for your son. I would like to think that if I was in the same situation, I could do the same.

**Ms WOOD:** You just have no choice, really. That is what it comes down to.

**Mr STIRLING:** Thanks for coming in and sharing that with us.

**Dr LIM:** Do not forget to leave us one of your submissions.

**Mr WOOD:** Yes, I will leave this one.

**Dr POOLE:** All right, thank you very much.

**Mr WOOD:** I just got a bit emotional about the bits in there ...

select COMMITTEE **ON EUTHANASIA**

**PUBLIC HEARINGS**

**Elsey Room, Parliament House, Darwin**

Monday 10 April 1995 Opened: 18.12 am

On the committee: Mr E. Poole, MLA Dr R. Lim, MLA Mr M. Rioli, MLA Mrs L. Braham, MLA Mr S. Stirling, MLA Ms P. Hancock, Secretary

Representative:

Dr J Zalcberg, Director of Oncology and Palliative Care,

Heidelberg Repatriation Hospital, Victoria

**Note:** This is an edited transcript.

**Issued: Thursday 4 May 1995**

---

**Mr POOLE:** I welcome Dr J Zalcberg, the director of oncology and palliative care at the Heidelberg Repatriation Hospital, Victoria, who is here to give evidence.

Doctor, other than in exceptional circumstances, witnesses appearing before this committee are not required to take an oath or make an affirmation. However, I remind you that the information that you give to this committee must be truthful.

I also advise that the committee has authorised for the purposes of this inquiry that the usual proscription on the disclosure or publication of material placed before the committee by witnesses does not apply. Witnesses do have the right to request that their evidence be taken in camera and/or remain confidential. Please advise us now if that is the case.

**Dr ZALCBERG**: I am happy for it to be in open meeting. I have a question, sir, about whether or not any members of the press are here, though.

**Mr POOLE**: Yes, there is. Oh no, sorry there is not. So, for the Hansard record, please state your full name and the capacity in which you appear today.

**Dr ZALCBERG**: My name is John Raymond Zalcberg. I am a medical oncologist, really representing personal views.

**Mr POOLE**: Doctor, if any journalists do appear, I will advise you accordingly. All right, if you would like to make whatever comments you would like to make, then we can ask you questions.

**Dr ZALCBERG**: Unfortunately for the committee, the flight from Melbourne is fairly long. I have a few things to say, but I will try to be brief and I shall be happy to answer questions. What I would like to do is tell you very briefly who I am, in terms of where I am coming from with respect to this debate, and my own personal experience in dealing with issues of euthanasia, in a philosophical construct which I think is a useful way to think about it. I want to tell you what currently happens in the medical oncology unit in Melbourne, and deal with some of the philosophical arguments, then specifically in terms of the bill. It sounds awful, but I hope it will not take too long.

Firstly, as you heard, I am the director of medical oncology and palliative care at what is now known as the Austin Repatriation Medical Centre. It is now the largest general teaching hospital in Victoria. All of my comments are about Victoria I do not have any experience of what happens in the Northern Territory. I conduct a laboratory research program and a clinical research program, and am the author of 80 papers and 50 abstracts. I am involved in 4th, 5th and 6th year teaching, and I established the first palliative care course in Victoria. In that course we defined principles of notforresuscitation orders of patients. That is a publication in the Medical Journal of Australia. Finally, just to round that off a little bit, I established the first artistinresidency program and the first music therapy program in an oncology unit in Victoria. So that is what I am, in a way. What I am not is a member of any political party. I do not belong to or represent a euthanasia society. I do not belong to or

represent the Right to Life organisation. I do not belong to any political or social group outside professional affiliations. I suppose the AMA is one of those, but I have not read their submission and I am not here to represent them. Finally, my own experience with this whole issue is about cancer. I do not have any experience with AIDS, I do not have any experience with people with motor neurone disease as a specialist physician.

After 15 years of looking after hundreds and hundreds of terminally ill patients, people who die, the one clear observation that I have made is that people want to live. They actually desperately want to live, in ways that make most of us who are well think: 'Why in the hell do they want to live?' They want to live they do not want to die. But they want to live without suffering, and they want to live with dignity. In my experience, requests for euthanasia have always been in the context of either unrelieved pain or unrelieved suffering. Just to give you a brief example I shall have a few anecdotes as we go through an elderly lady with a tumour in her arm, who had a lot of pain, asked us about euthanasia. This was in the early days, early for me in terms of being a specialist, and before the debate became widely publicised. We were unsure what to do about this, but in the process tried to alleviate her pain. The pain would ease. We would go back and say: 'We had better sit down and talk about this request for euthanasia', and she would not want to talk about it. And then her pain would recur over time, and she would say: 'I would like to have that discussion'. This happened 3 or 4 times, until ultimately we were able to get her pain control right and the request for euthanasia disappeared.

So, philosophically, if you take the belief that people want to live, but without suffering, then the solution, for me at least, is not to make the problem go away by killing patients. I do not mean that in an emotive sense, but in the sense of euthanasia. The solution is to alleviate the suffering. I shall come back to the concerns about that.

Those arguing for euthanasia will respond to that philosophical construct that is, if suffering is a problem let us relieve the suffering, let us not take the problem away. The obvious 2 responses that come forward are firstly that goodquality palliative care is not always available, and that even goodquality palliative care cannot alleviate the problem. I would like to deal with the two of them separately.

Firstly, it is not available. It is true that in many parts of Australia it is not available. In the Northern Territory, as this committee no doubt has been told many times, palliative care is very, very underdeveloped. But I am talking about Victoria, as I said. Even in Victoria, where there are hospices and there are palliative care positions and there are palliative care units, it is not necessarily widely available to members of the public. But to say it is not available frightens the hell out of me. And it frightens the hell out of me because it has taken an awful lot of effort to get what we have, in terms of government support and funding for these sorts of groups like palliative care. And as you will see when I start to go through some of this, goodquality palliative care is expensive.

What concerns me is, will the pressure to develop goodquality care be there, if we actually get rid of the problem in the cases that we cannot deal with? Will we be tempted to accept the status quo? The status quo is not good enough. People die, and some of those people die in suffering. If we are going to alleviate that suffering, we cannot accept the status quo. And if good palliative care is a solution to that, at least in part I shall come to when it fails in a minute we are going to have to spend money, we are going to have to provide resources.

I have the utmost respect for people like Rod Syme, who was the first person I ever worked for as a doctor, and I believe he is very sincere about what they are saying. But if we get rid of the problem, the pressure to develop goodquality palliative care is going to disappear. For example, it might be reasonable to suggest that out of this whole exercise, palliative care may grow in the Northern Territory. If euthanasia was already here, I suspect it would not happen. Anyway, these are personal beliefs. Of course, I also come from a sort of academic base. I believe that where we fail, where we are not good enough at doing things, we have to spend time and effort and energy in trying to do better. We have to carry out research, new techniques, new approaches, understand what patients think. Again, the resources to do that, I believe, will not appear if we can 'get rid of' the problem.

The second issue is that even with good palliative care, it does not always work. That is true, and I shall come to it in a minute. The problem is, who decides that it has not worked? Most medical practitioners are not well trained in communication. I include myself in that. When I went to medical school, there was almost nothing on communication. I am 43. There is a whole generation of people out there who have not had training in communication. They are not trained in palliative care there was no palliative care training when I went to medical school. They are not trained in the use of opioids, drugs like morphine. Many have difficulties in spending the time to allow patients to talk about fear of the unknown, to allow patients to talk about their fear of dying. We are all afraid of dying, but when you are closer to it you are more afraid. You need to sit down and hold the patient's hand and talk. How many medical practitioners have the time to do that to help patients talk about their remorse, and their loss of family, and so on? Yes, it is true that goodquality palliative care does not always work. But who is going to decide that patients have goodquality palliative care, given a major problem in the training and the experience of our medical fraternities that currently exist.

We are a specialised unit. We treat people mostly with advanced cancer. We have 20 beds, at any one time all occupied by people with advanced cancer, year in, year out. I have done this for 10 years. When I see a patient who is difficult to manage I do not mean requesting euthanasia, but with problems that are difficult to resolve they are seen by a liaison psychiatrist, and/or a nurse counsellor, and/or a chaplain, and/or the list goes on. A lot of people, expensive. We meet with the patients and we meet with their families, and we try to tell them what to expect. We try to alleviate their fear, their remorse.

I believe it is this fear of the unknown that creates the helplessness. I do not believe that it is not being able to wipe your bum, or some diarrhoea, or not being able to get out of bed that necessarily makes you helpless. There are whole lots of people on iron lungs, polio victims. We do not hear about them asking for euthanasia. There are people that are quadriplegic, paraplegic. How many of those have we heard that have requested euthanasia?

A few, I agree, but not an awful lot. Either they are all inhibited by the restrictions on talking about this, or they do not necessarily think about this as an issue, provided they know where they are going and what is ahead of them.

What goodquality palliative care is about is bringing in people with particular skills, often not doctors and usually not doctors. Even when they are assessed by psychiatrists, a psychiatrist tries to identify who in the team is best going to be able to deal with it. Is it a spiritual issue? Is it an issue of dealing with family? Is it about talking to your children about dying, about talking about what you want them to do? They are very difficult things to do very difficult for doctors who are often not trained to do it, and often difficult for doctors who do not have the time to spend.

So, it is true that goodquality palliative care does not always work. And the problem is, who decides that someone has had goodquality palliative care? Have they had adequate resources put into dealing with their problems? The response to that, by people like Rod if he were sitting here, might be: 'We want to restrict euthanasia to people who have had goodquality palliative care'. Again, the problem is who decides. Not only do medical practitioners and I am one of them, and I know Dr Lim is also a medical practitioner often not know what represents goodquality palliative care, the real problem is that they do not know that they do not know. I am sorry to say it that way, but that is what it boils down to. You do not know. You think you are going a good job 'I'm doing the best I can'. But are you? If you think you are, you say you are. If you are a paternalist or you have to adopt an attitude of having all the answers ... A lot of doctors cannot say they do not know. It is hard to say, 'I do not know', when you are expected to know. No one distinguishes the GP from a superspecialist and the superspecialists often do not know. That is the problem about goodquality palliative care not always working. How do you decide what is goodquality palliative care? Can you necessarily assume that medical practitioners A and B, as talked about in the bill, actually know that they do or do not know?

At least 2 or 3 times a week, I will see patients who are suffering. They have been badly advised or they have been not advised. They are in horrendous pain and they are suffering. If it is not physical agony, it is psychological agony. They have pain that is present all day every day, all night, night after night after night. You wonder how in hell their spirit allows them to continue. These are people who have been seen by our doctors. I am not saying I am better than them, but I happen to be at the end of the road, so they come to me with these problems. They have been seen by surgeons, they have been seen by GPs, they have been seen by other physicians.

Why are they like this, if we all know how to practise goodquality palliative care? Rod has talked to me about this. He believes that goodquality palliative care is something that every doctor should be able to do. When we started our palliative care unit, we said: 'This is a consultative unit. We will teach everyone goodquality palliative care, and we will selfdestruct. We will not need a palliative care unit any more, because everyone will know how to do it'. But it is not like that, it just does not happen like that.

---

What I am trying to say this is why I was concerned about the press is that I cannot emphasise to you enough how much variability in knowledge and, dare I say it, ignorance, there is about cancer and all I know about is cancer in the medical profession outside the particular specialties involved. My problem is that I think some patients ought to have the right to euthanasia. That is my real position. But I have a real dilemma, because I am concerned that there will be a medical carnage. I am concerned that doctors who think they are doing the right thing, and want to do the right thing, and mean to do the right thing, will say, 'This person has had goodquality palliative care, this person has 6 months to live', and they are wrong, and they will not know they are wrong. They will mean well, but they will not know that they have had goodquality palliative care. They will not know that their prognosis is absolutely way off, like the gentleman we just heard. That is my concern about the bill.

Now, another observation that I have made as an oncologist is that relatives and family suffer a lot. It is obvious to anyone. We heard a very potent example of that just a moment ago. It could be argued that the suffering of families would be alleviated by euthanasia. But I am not sure that it would. The worst problems of bereavement occur after accident and after suicide sudden death. I have found that the time that families spend with loved ones is really an important part of their future rehabilitation. They do not necessarily feel it at the time. You cannot go in there as a paternalist and say: 'Don't worry, it is all worthwhile, it will be worth it at the end'. One does not say that. Sometimes it is true and sometimes it is not true, but I actually feel that you see plenty of examples of it.

Again, if I might give you an anecdote, a patient I can recall who had advanced cancer had a lot of trouble dealing with her death. It turned out to be a problem in communicating with her daughter just being open about dying, what would happen, what the future was and so on. We spent some time with them as a group, and ultimately the daughter came and spent some time with her mother, and in the end spent all her time with her mother. At the very end, she actually slept in her mother's bed. I had never seen that before as an oncologist. She spent the night in her mother's bed in hospital. And then all of a sudden the daughter disappeared we did not see her for a week. Her mother gradually deteriorated, got sleepy and died. I think the daughter had said her goodbyes. Now, if this bill had been available and we could have organised euthanasia it was not requested, but it might have been would that have happened? I cannot tell you whether or not that daughter is better off. Those sorts of studies are still very fledgling. They are needed. Time for families is very important.

There was a survey, no doubt quoted here, of 4000 deaths that occurred in the hospice movement in the United Kingdom. Relatives were asked: 'Was euthanasia requested by your deceased relative?' Of these 4000 deaths, 3% of the relatives said that the person who died had talked about and asked about euthanasia. 27% of the relatives themselves thought euthanasia would have been a good idea, or an earlier death would have been a good idea. Maybe it would have been, maybe it would not I would not pretend to be the judge but what is the knowledge base of people saying this? Would they really have been better off if euthanasia had occurred? I do not think we know the answer. But there are clear differences between what patients ask for and what relatives expect.

---

Rodney Syme was talking about the 12 days it took someone to die. I have seen family members come in, sit there for hours, hold hands, cry, talk to each other, reminisce, occasionally see a flicker and think that they are communicating with their loved one. I am not sure that that time is lost or wasted. I am not sure that the patient would necessarily have been better off dead. Again, it is a personal observation, but I think it is another perspective on the way that this is put.

Those are the arguments about euthanasia. I would like to tell you what happens in my unit in terms of current practice, what I believe happens in a lot of oncology units around the country. From the diagnosis of cancer, patients go through a range of stages. Each stage requires that you identify goals of management. So if a patient has been identified as having a bowel tumour, the goal of management is to cut that bowel tumour out. Those stages of goals of management have to be negotiated with patients. You do not just do things to people. You discuss what you have found, what you would like to do, why you think it will benefit, why you think it will not benefit and so on. You discuss it with a patient and their family.

The goal of management in the case of the bowel tumour was cutting it out, so the patient is cured. But ultimately in many patients and we are talking about thousands of patients who die every year in Australia of cancer the goals of management become maintenance of quality of life by symptom control. That is, let us look at symptoms, let us control symptoms in order to try to maintain the best possible quality of life. There are several principles that need to be understood principles that I find I need to remind myself of on a regular basis. It is not that I am trying to tell you. I have to tell myself these, as often as I have to tell the residents and so on that I work with.

Patients decide about quality of life not relatives, not doctors, not nurses. Very often relatives will say, or we as health care providers will think, this must be a terrible situation to be in. All of us have hopes and aspirations. I hope to see my grandchildren one day. My daughter is 16, so I hope that is a fair way off, too. But when you are sick you have different aspirations. You might just want to make it to Good Friday. You might just want to make it till your daughter comes back from England next week. The aspirations and the hopes of the people who are sick are quite different to those of people who are well. And yet, people who are well are trying to project what it must be like. It must be horrible to be paraplegic. I would rather not be paraplegic, but paraplegics do not all say, I believe, they would be better off dead. They would much prefer not to be paraplegic, I have no doubt about that. I am not sure that death is the solution.

What I am getting at is that people's hopes what they want out of life, their sense of meaning, their sense of dignity differ depending on their state of health. The implication of this observation is that when surveys are done and there are lots of quotes saying the Australian public wants X, doctors all believe Y, nurses all think we should do something else what we are seeing is a projection of what we, as well people, think. We do not ask dying people what they want. It is hard to do that. It would be interesting, but I am not sure possible to do. We as well people cannot, I believe, come to any real conclusions about what is the right thing to do with people who are sick, because they have different aspirations. We

are coming from a different place. It is an important concern, because we are treating sick people as having no opinions. We are saying that we as well people think it would be wrong not to be able to go to the toilet. But people who are ill do not necessarily feel that. They may do, but they may not. Until we know what they think as individuals because it is ultimately an individual thing I think that surveys are not very useful and often not very insightful.

I might say, as an aside, that recently the bioethics centre at Monash asked me to participate in a survey done by a student. I have no idea whether it was typical of previous surveys, since I have not participated in those, but it was seriously flawed. It very clearly had a direction that you had to end up in. It was a bit like going through a maze: the arrows were there not that obvious, not in black and white, but they were there. It worried me a lot and I said the study was not ethical. I do not know what has happened to it.

I am coming back now to what happens. The first thing is that we develop these goals of management. The second is that we decide on quality of life as the prime endpoint at a certain stage of disease. As I said previously, the patient decides. All treatments are directed at symptom control, so we give as much pain relief as required. We give fluids if people are thirsty, but if they are not thirsty we do not give fluids. Now you might say that people are unable to say whether they are thirsty or not, but often the relatives and nurses will say that they look like they are licking their lips or something. There will be some clue. If people are thirsty we give them fluids, not intravenously. I am talking about people who are seriously ill, in the last weeks, if you like, of their life. We can come back to time later. We do not do blood tests and we do not do Xrays, unless we think they are required to understand a symptom that we can do something about.

We give as much pain relief as required. If that pain relief causes change in consciousness and I will come back to this in a bit more detail then so be it. 60% to 80% of patients with advanced cancer will have pain at some point during their illness. But that figure does not mean uncontrolled pain, that people will die in uncontrolled pain. The figures on how many people have uncontrolled pain at the very end of their life vary. It depends on where you look and all sorts of things. But I think it happens very, very uncommonly. I would not insult you by saying that it never happens. Never say never is an old dictum in medicine, and I think it applies to this as much as anything else. It does happen, but it happens very uncommonly. When we do have a pain problem, we involve a physiotherapist, we involve a psychiatrist, maybe, depending on the problem, an anaesthetist, a neurosurgeon.

I am terrified by doctors who do not know how to treat pain but again, do not know that they do not know. 'We are doing what we can, Mrs Jones, this is the most effective drug available'. Do they know the 13 different neurosurgical approaches that can be used? The 15 different anaesthetic approaches? I am just plucking these numbers out, obviously, but there are many anaesthetic approaches to treat pain. There are many neurosurgical approaches that can be used. I do not know them all, and I am expected to know them all. So again, with doctors who do not know that they do not know, we are going to have them say, 'We are doing the best we can', and it is not necessarily the case. The expertise is available. In some places it is available physically, in some places it is available in the literature, it is available on

the phone, it is available electronically, it is available. I do not know how to suggest what to do for the Northern Territory. I understand that with 180 000 people it is not the same as 3 million. I do not know what the solution is and would not pretend to try to give you one. I am just giving my feelings about what happens in Victoria.

Morphine is not well prescribed by doctors, including specialist doctors. Part of the reason relates to federal and state government regulations. I do not know about the Northern Territory, but certainly in Victoria they make it difficult. I rang the chief pharmacist in Victoria recently about this issue and he said: 'We must watch out for these drugs of addiction'. Morphine is not a drug of addiction if someone is dying of cancer. It should never be called a drug of addiction, but that is how they think of it. The cynicism, of course, of the federal government I do not belong to a party, this is my own observation and I have published on it is that morphine ... The gentleman just spoke about getting 5 days' supply. Every 5 days he had to go back to a doctor and get another prescription. Why could he not get a month's supply? Because the federal government has put restrictions on the supply of morphine, which I believe is about cost. Sorry, I have diverted.

So, coming back to what we do, we have people who are in pain and we are required to use morphine. We will start them on morphine and use it freely. We might start them on a morphine drip. The morphine drips that we use now are almost always given subcutaneously, under the skin, as an infusion. The patient has a little portable thing that they can walk around with. We have had people go to work with infusions of morphine. They are quite sensible, they are able, although we tell them not to drive. They can function. But in patients within days to a few weeks of the end of their life ... I emphasise that I do not call morphine taking their life. I believe it is the natural end to their life, since it is not the morphine that is the cause of the problem, it is the cancer that is the cause of the problem. The morphine is being given to treat their pain, although I believe you can get into a philosophical argument about that. But when patients are within days to weeks of the end of their life, and their general condition is poor and they have lost weight, it is true that the introduction of morphine can lead to an alteration of their conscious state, no question about it. We accept this as an inevitable effect of treating pain at the end of people's lives, determined by their disease not determined by us, not determined by the relatives or anything else, determined by the process.

If the pain is well controlled, the dose of morphine is kept constant. If the patient is awake, we consider that to be a bonus. But if the patient is not awake at the time their pain is controlled, we accept that as an inevitable consequence of what happens. Is that euthanasia? We give morphine and we wait till their pain has gone, and then we stop increasing the dose and we keep the morphine going. Is that euthanasia? I think Rod would say it is. I believe it is symptom control. If you tell me that morally it cannot be distinguished, I do not feel it is worth the argument. If that is euthanasia, then yes, we practise euthanasia.

But if we did that to someone 3 months before the end of their life, they would not go unconscious. That is the difference. We are talking about people who have reached a certain stage. It is not possible to define it very clearly. But if you knew someone had 3 months to go, and I will talk about that in a moment, giving them morphine by infusion to control their

pain, they are not the people that go unconscious. They are the people who say they are a bit dopey, and you say you will bring the dose of morphine down. They are the people who get pain control and say: 'Now I would like to go home, Doc'.

I see that as good medical practice. I do not see it as euthanasia. But in the end people will call it what they wish. And you see, to practise the way I have just described, I do not believe you need to change the law. I think what we do is accepted by the legal profession, accepted by the community, accepted by the church I am talking about Victoria and accepted by the Right to Life Association. I do not believe that people, if I were to describe this to the Right to Life Association, would object, though I have not done it.

We often tell people that is what we are doing. I go along to Mr Jones and say: 'Your pain has been difficult to control. I am going to start you on this morphine drip. It might make you drowsy, is that okay?' And people who are suffering do not often have a choice. It is all very well for me to ask if it is okay, but what choice do they have? It is very difficult. Nevertheless, people often understand what is involved by doing this, I believe, and in a sense it is consent. We tell the families all the time why we are doing it and what we are doing.

There are patients with problems that are hard to fix. Weakness and debility are the sorts of examples that we have heard about today. Our approach has always been to try to reassure patients that they will not be left alone. We try to encourage families to express their love for each other and concern. We have tried to assist families to be together, to touch each other, to hold hands. We try to get nursing staff or other staff, the health care providers, to do the toileting so that in a way this issue of dignity, who is doing what, if your son has to clean you up or the nurse has to do it. We have a view, anyway, that if the family can go out of the room and the patient gets cleaned up, the family come back in, what is undignified about the patient? I do not believe there is any loss of dignity in that sort of process.

In a sense, to me, the philosophy is life with dignity, not death with dignity. Once death occurs it has occurred. It is a bit like being asleep none of us knows what happens. Death is part of living, and it is life with dignity that we aim for again, a somewhat philosophical argument.

We communicate to patients what we hope to achieve, what we are doing, why we are doing it. People know after we have spent time with them what to expect, as best as we can possibly tell them. They are treated like human beings, not as tumours out of control. They are treated with respect, they are treated with compassion. We make sure there is enough time to be listened to. It is not always the doctor who does the listening, but when the doctor does it he sits down with the patient, eye to eye, and listens. I believe that that provides a lot of this issue about dignity.

Now, is that happening all the time? I do not know. Have we set standards that we cannot achieve ourselves often enough, let alone the rest of the community? I do not know. That is what I think we have to aim for. Again, we find ways to overcome helplessness

because, as I said previously, I think helplessness is a lot about not knowing where you are going or what is ahead of you and not understanding. As best we can, we try to explain that to people. We make sure they do not feel they are a burden.

As you can see, this is intensive medicine. It is intense medicine. It is rewarding medicine, I might add. We help many, many patients. Again, I am scared that carte blanche I use the words loosely euthanasia will take this away, provide us an easy way out, that the funds for this sort of intensive, resourcerich palliative care are going to dry up, and that with all due respect, ladies and gentlemen you will not spend the money on this sort of level of palliative care that is required, that can achieve this. I might add that in Victoria it is a neverending battle.

I want to come to a couple of philosophical arguments about euthanasia that have been put up by various people. The first one relates to autonomy. I do not believe that true autonomy really exists. We have freedom of speech but. We have freedom of movement but. For example, you cannot go into a theatre and yell: 'Fire!' There are things you cannot do. Everything we do is a balance of personal needs versus the needs of the community that we live in. So then comes the question, should people have the right to decide when to end their own lives? That is the issue of autonomy. It is not about terminally ill. I do not have an answer to that, that is up to society. I would not try to indicate what the answer should be. I think we should not confuse that with incurable disease. If we are legislating for autonomy, we are saying that I have a fundamental right to decide when I live and when I die. Fine, then let us say that. But let us not tie it up with incurable disease and terminal disease.

I cannot see the logic of advocating autonomy, and then talking about 12 months to live. As we just heard, the 18yearold restriction ... It will be a 16yearold, the parents of a 16yearold, who will come. How long will it be before those arguing in favour of autonomy will talk about the person with a diagnosis of Alzheimer's, who knows that he is going to assume a vegetative state? Are they going to have the right to euthanasia? They have more than 12 months to live., so that is about autonomy. The proponents of this argument of autonomy say, at the same time, that there is no slippery slope. But surely this is the slippery slope. We are not stupid. If autonomy is what it is about, then the 16yearold, the lady with Alzheimer's who has 5 years to live but is going to be a 'vegetable' I hate to use the term are going to be part of this slippery slope. I think it is ridiculous to assume that there is not a slippery slope. I do not have a problem with a slippery slope, personally. I think if we are going to say legislate for autonomy, then that is fine. But that is what it has to be about not hiding it and saying it will not happen. I think it is silly to think it will not happen. It clearly will happen, and will happen very soon.

A prognosis of 12 months is in the bill and is often talked about. The philosophers talk about it. I would like to dwell on that for just a moment. Every day of the week, I see patients who have been incorrectly advised about their prognosis. I saw a lady a number of years ago who came to see me after another physician told her that she had 2 days to live. They came in a state of utter terror. 2 days to live complete arrogance on the part of the person who told her, and stupidity. She is alive 5 years later. She has never recovered from that nightmare. She still does not sleep at night. With all the counselling and all the support we have been able to provide her, that living nightmare comes back and curses her.

---

Last week, I saw a man with secondaries in his liver, metastases from colon cancer. I looked at his CAT scans from 12 months previously and could not believe he was still alive. I am supposed to be an expert. If you had asked me 12 months previously, after I had looked at the films and looked at him I do not always go through this exercise, but I knew I was coming here I would have said he had 3 months. I would have been able to convince any other medical practitioner you like that he had 3 months, no doubt about it. Firstly, I am supposed to be an expert. I may or may not be, but I am supposed to be. Secondly, he had a big tumour in his liver.

So doctors are very, very frequently wrong about prognosis, and it is not only inexperienced doctors who are wrong. . I am wrong more often than I am right. I try to avoid ever giving a time to a patient. I learned that the hard way, because I learned that I was wrong. But you do not know that it is wrong until it has happened. You do not know that this guy is going to be alive in 12 months until he is alive in 12 months. Meantime you thought he had 3 months to live. And if doctors are wrong about prognosis, and they do not know they are wrong and that has been a common theme, I guess and they cannot admit they do not know, especially if they are supposed to know ... I am supposed to know these things that is what people expect from going to see a cancer specialist. So doctors do not know, they do not know that they do not know, often they cannot say 'I do not know'. These are the people that are going to be telling us: 'It's okay, you are within 12 months. It's okay to think about euthanasia'.

How many of these doctors read the literature? We get 10 cancer journals a week in my department, 10 different journals on cancer. I try to scan all of them. I will not pretend to you that I read them all, cover to cover. We do a computerised literature search, weekly, of the entire data base that exists in medicine. How many GPs receive a cancer journal on a regular basis? I hate to say it but with all due respect, I suspect not many. How many of them receive a palliative care journal, where these sort of issues are at the coalface, being discussed, being worked out, being resolved? They might get it when it gets into the local journals, but that might take some time and it depends on what is selected. And do you think that a colo-rectal surgeon reads the breast cancer literature? Do you think that a urologist, with all due respect, reads about the latest pain techniques? I think they would like to, but there is so much information around it is impossible. When you are a specialist, you are restricted to your own area, and even within that area it is extremely difficult to keep up to date.

A patient goes to see a specialist. The specialist says he has 3 months to live. How does the GP know that the specialist knows what he is doing? I talk to colleagues and friends who are GPs, who say: 'I don't know how to refer patients because I do not know who is a good oncologist and who is not'. How do we know that? The previous gentleman, who is not here, said: 'I sent him down to Adelaide for the best treatment'. I am not saying it was not the best treatment, but how do we know? I do not know, and I am sure that you may have difficulty in knowing. And yet, we are going to let any medical practitioner make statements about prognosis, statements about good palliative care.

---

If doctors are wrong and they do not know they are wrong, this is the problem I have with the legislation. The response will be, let us build in safeguards. Let us build in all the safeguards that you would like to suggest, and we will make it work. The trouble is, I doubt it is possible. I have a real problem in dealing with the patients that Rod was talking about. The few patients, and there are a few of them, that can and do make a rational decision I believe that there are some of those patients around. I have seen very few of them in 15 years of practice, but I believe it. I am talking about cancer now I do not look after AIDS or motor neurone disease. But have they had all the access to all the sorts of things I have been talking about? I am not sure that they always have. Yes, they make a rational, informed decision, but I am really not sure that they will have necessarily seen a psychiatrist, seen a palliative care physician, and seen the ones who know what they are doing.

I should add a mention of psychiatric illness in cancer. About 40% of patients with cancer have an adjustment disorder, have alterations in mood. The way I think about it is that all of us have mood levels that swing about a norm. We have good days, bad days and so on. When you have an adjustment disorder, your swings are much greater. But you are not depressed, you come back to normal. In true depression, your moods come down and never go back to your norm. Rod says every doctor knows how to assess that. I wish it were true. I personally have a lot of trouble in assessing it. I suspect a lot of doctors have a lot of trouble in assessing it. It can be very difficult.

In closing, I would like to talk about the bill specifically, on a few of the items. This is item 6, and the first is about this issue of 6(b): 'The medical practitioner is satisfied, on reasonable grounds, that the patient is suffering from a terminal illness and is likely to die within 12 months'. I have told you of the concerns I have about picking prognosis, people not knowing that they do not know. Even the experts are wrong, often wrong. Now, if you say to me this bill is really about people within the last week of their life, that is a different matter. But it does not read that way. I am horrified that someone will come in and say: 'I saw my surgeon and he said I had 612 months'. Will he be able to convince somebody else that he has 612 months? No doubt in the world, he will. We have networks, we have doctors controlling information. We have a limited knowledge base. We have similar professional training and lack of professional training in cancer. That is what terrifies me this person who comes in and says a surgeon says he has 612 months, and at the end he is going to have bowel problems and so on, so he wants to have euthanasia. And the GP says: 'Fine'. Again, does he know if the surgeon has any qualifications?

The second medical practitioner does not have to have any special qualifications either. It could be a poorly trained doctor like me. Medical school training did not teach you about communication, did not teach you about bereavement or dying, or any of those sorts of issues.

If 'the illness is causing the patient severe pain or suffering or distress', what has been the palliative care input? The next item deals with that. It says: 'The medical practitioner has informed the patient of the nature of the illness and its likely course, and the medical treatment, including palliative care, that might be available'. Again, that frightens me. It might be available if you go I am sorry again for the isolation of the Northern Territory to Adelaide.

Families want to be together at this time. People do want to die at home if possible, families want to be together. 'Mrs Jones, you could go to Adelaide, or you could go to Melbourne to my hospital, or you could go down the road and see the palliative care physician, but I do not think that they can do much more for you'. That is what concerns me, that people will not get the access to palliative care that they really need.

The next item was the issue that the patient is competent. Again, I think it is very difficult to assess that, particularly in people who are sick. Numerous times I have heard doctors say: 'Of course you are depressed you are in a terrible situation'. But it is not 'of course you are depressed'. 10% to 20% of people are depressed. It is very hard to figure out who is and who is not.

Finally, the only other concern I have, specifically about item (i), is that there is not an opportunity for people to change their mind. There is not the opportunity for things to evolve with time. With various sorts of input, with palliative care, say, or with a change of medication, maybe the pain would disappear and maybe they would feel differently.

Those are the specific things about the bill. I have a final comment. I am sorry I have gone on for so long I told you it was a long flight, so I had a lot of time for this. I did tell you that I felt that in some patients very few euthanasia may have a role to play. But I do have concerns about the introduction of legalised euthanasia in terms of the morality of society. I do have concerns about the likelihood of pressure being brought to bear on patients to take an easy way out. It might be that it is all done wellmeaning, and patients will think and families will think it is going to make it easier. But as I said previously, for families, I am not sure it will make it easier. I do not pretend to be an expert in those things. I simply raise them as concerns.

Finally, I quote from the Bulletin of 22 February, an article about euthanasia entitled, 'Praying for a Merciful End'. As a doctor who thinks that money for medicine and money for research should be unlimited, and that is the extent of my naivety, let me read you this: 'In hospitals and nursing homes, the vegetables [that is their word] occupy thousands of beds. It is going to change, of course. In another 10 years the country will not be able to afford its living dead. "It's ironic, but what ultimately will bring acceptance of euthanasia will be the dollar", says the matron of 1 Brisbane nursing home. "It will become a matter of simple economics".

Goodquality palliative care is very expensive. I hate to see that not happen, because of a bill for euthanasia. I understand and I care a lot about the few people that might be better off with it. But there are a lot of people who might get hurt along the way.

**Mr STIRLING**: Doctor, I think the evidence supports your case. In the case of the Netherlands, at least, there would appear to be a paucity of palliative care [inaudible] history of the regulations covering euthanasia. I share your concern that if you legalise before you put palliative care in place, you are probably never going to see it. The problem we have in the Northern Territory, of course, is not only a small population over a vast distance, but also the

---

scattering of people in remote rural areas. Given I am not sure how many times you reminded us the cost of palliative care, it is an even greater concern in the Territory because quite clearly, outside probably Darwin and Alice Springs we are not going to be able to resource this.

**Dr ZALCBERG**: Yes. As I said, I would not pretend to have a solution. On the other hand, the first thing is to acknowledge the difficulties, and the second is to say and I would ask this rather than say it has not happened is to ask what attempts have been made or can be made to resolve the issue of rural communities? It is not just the Territory. It is rural Victoria, it is rural New South Wales. It is a problem for all of Australia, really. I do not pretend to have the answer, but my simplistic response is, let us sit down and say we have a problem. We want to provide goodquality palliative care, we as a government or whatever. How do we do it? Let us get some people together and work it out. I do not believe it is insoluble.

**Mr POOLE**: As soon as this debate started, really, even Marshall Perron stood up straightaway and said one thing that is highlighted is the lack of palliative care in the Northern Territory, and we must address it. I think certainly this committee will be making strong recommendations along those lines, anyway, whether the bill goes or does not.

**Mr STIRLING**: I thought your point about autonomy and the slippery slope was a very good one. There is a lack of honesty, I think, on the whole, because there is no doubt that if the bill was enacted they would be back to say what about those people I am not sure if you are familiar with the quite famous Canadian case of the ALS sufferer who are locked outside the legislation, the under18s, for example, or victims of motor neurone disease where it is not possible to say 12 months, the quadriplegics who cannot adjust. Every one of those cases has just as legitimate a claim, if you are going to have euthanasia, as the terminally ill with 12 months or less to live. That is a fact, as sure as the sun is going to come up tomorrow. And there is the slippery slope.

They have talked about [inaudible] Nazi Germany, but you do not have to go into that emotion and rhetoric. It is simply a case that the bill will be expanded, or the legislation will be changed over time. I know that your view, Mr Chairman, is that if that is the state of society and the community moves that way, of course, then the legislators are backing community opinion and that is the way it goes. But there is a lack of honesty, I think, in that approach.

**Dr ZALCBERG**: Yes, I have been surprised. I went to a debate in Melbourne where Robert Young, who is a philosopher at Latrobe University, was talking to that guy who came out from the Right to Life organisation. I did not think highly of him, but Robert Young was almost treating us like fools, with a whole lot of discussion about the philosophy of autonomy and then saying we are talking about 12 months. I agree with you: if the community is ready to legislate for autonomy in respect to when you die and when you do not, I guess we will have to accept that. That is what the community standards are, so be it. But I think it is wrong to say that it will not happen. I just do not see how it is possible not to happen. If we are talking about autonomy, people with Alzheimer's will of course people will start to talk about it.

---

Of course, the difficulty is that a lot of people with these sorts of diseases do not know what is ahead of them. None of us really know. They will be making decisions much earlier than they might otherwise have done. Lots of people have written in letters to the editor saying that if euthanasia had been available at this time they would have taken it, and they are glad they did not. When you do not know what is ahead of you, that creates a feeling of helplessness, of uncertainty. People are going to say: 'I want out, I do not want to go through that'. And the helplessness starts today. It does not start when you cannot get out of bed, it starts today because you do not know what tomorrow is. I think that is a real problem. If we start to think about how many people we are talking about like this, the numbers are going to be large.

**Mr STIRLING**: The Monash Bioethics Centre survey [inaudible] not quite ethical in your view?

**Dr ZALCBERG**: I did not think it was ethical. The ultimate in ethics to me is if you are asking a scientific question, you have to be able to get an answer. Even if it is only a questionnaire, if you do something to patients or to people which does not allow you to get an answer, then it is not ethical to do it. It is a bit like giving a treatment that you know will not work, it is not ethical to do that. So to me, at least, this was never going to allow people to answer honestly, because it did not allow for a third answer: 'It depends'.

Do you always believe in telling the person the diagnosis? Yes, but it depends. And when I say, 'It depends' I mean, 'because they do not necessarily have to know everything today'. These things occur over time, not everyone is ready for it. You say, 'It looks like there is a cancer', and that is all that some people can hear. There is an explosion in their head you can see it. You cannot see the sparks, but you can certainly see the explosion. That is time to stop. It is time to sit and see how they feel about it, and say: 'Come back with your family tomorrow', if they are not there they should be there.. So, do you always tell the patient the diagnosis, do you believe in that? Yes, but it depends. 'But it depends' was not allowed in the questionnaire. I think that was a stupid question to ask. It was quite clear where you were going. There was this maze, but there was the end and that was where you had to end up.

**Mr POOLE**: We have had a couple like that.

**Dr LIM**: More than a couple.

**Mr STIRLING**: Just another point. You are not the first witness to put to us that morphine is not well prescribed in a lot of cases, and there is this fear of addiction. When a person has a very short time to live it is a lot faster.

**Dr ZALCBERG**: Basically what we have tried to get across when we talk about morphine is that it is a strong painkiller for strong pain. That is it. But there are a lot of doctors, a lot of patients, the community, who do not accept that. 'Morphine means you are going to die', so it is left till later. 'Morphine is addictive', so it is left till later. It is hard to

get. Governments I do not know about the Northern Territory, but certainly the Victorian government and the federal government make it hard to get in enough quantities. I ordered a litre of morphine the other day for a patient. The pharmacist would not dispense it because you are only allowed 200 ml on the NHS and I had not filled the right form in, I did not get the authority and all that sort of stuff. In the end, this pharmacist broke the law. Governments make it hard to get, but it is not just governments it is the patient's attitude, it is the community attitude and it is doctors' attitudes. And when you make it hard to get, people will not use it. Human nature.

**Mr STIRLING**: Thank you very much.

**Mr POOLE**: Thank you very much. [Inaudible] really appreciated. *Last updated:*
You are the visitor to this page.