RIGHTS OF THE TERMINALLY ILL BILL
(Serial 67)

Bill presented and read a first time.

Mr PERRON (Fannie Bay): Mr Speaker, I move that the bill be now read a second time.

The issue of euthanasia is not a new one and, in recent times, public debate has escalated in various parts of the world, including in Australia. The reason for this resurgence is generally attributed to a number of factors:

- an increasingly educated and assertive patient population;
- an ageing community which is thinking more about death and dying;
- less traditional religious authority;
- more liberty and a strong belief in the right to choose;
- increasing numbers of deaths from cancer and AIDS and ongoing limitations in what can be offered with palliative care;
- and tremendous advances in sustaining human life that, in some instances, prolong the dying process.

Those factors are, of course, all present in the Territory.

This is not a political issue; it is a human rights issue. I began preparing this bill after searching thought about the rights of those who face a distressing, undignified and possibly painful death and the dilemma confronting them and their medical advisers on the question of whether or not to actively terminate life. Through the laws in place today, society has made an assessment for all of us that our quality of life, no matter how wretched, miserable or painful, is never so bad that any of us will be allowed to put an end to it. I am not prepared to allow society to make that decision for me or for those I love.

I am keenly aware that, in other forums, this issue has been debated for many years and that usually such debate has been inconclusive because it has split the medical community and drawn opposition from
some religious leaders. As a consequence, the emotion generated within the community has caused the politicians to back away. We have seen some of that debate in recent weeks since I announced my intention on 1 February. I asked at that time for those involved in the debate not to reject this measure outright for emotional reasons, nor to be irrational or to attempt to portray the bill as making lawful actions which it does not. This bill is based on a relatively simple principle: if there are terminally ill patients who wish to end their suffering by accelerating inevitable death, and there are sympathetic doctors who are willing to help them die with dignity, then the law should not forbid it. There are such patients, and there are such doctors, and the law does forbid it.

Honourable members will be aware already that this bill proposes the decriminalisation of voluntary euthanasia for a very specific group in our community under a very specific set of conditions. I have opted for this course deliberately. The vociferous non-religious opposition to voluntary euthanasia is based largely on promoting fears that patients, who do not wish to have their death hastened or who are unable to communicate or make a decision for themselves, will inevitably become victims under the liberalised law. Let me dismiss those fears. The bill I have introduced provides for no such thing.

Under the proposals contained in this bill, a person asking for assistance to accelerate their death is in total control of the process, and that person must:

- be an adult;
- be terminally ill and diagnosed to die within 12 months;
- be mentally competent;
- and must make the request in writing.

The patient must be advised also about the nature of the illness and its likely course, and the medical treatment, including palliative care, that is available. The patient must be experiencing severe pain or suffering or distress with no medical treatment reasonably available and acceptable to the patient to offer relief.

Before the patient's request for assistance can be met, a second medical practitioner must examine the patient, confirm the patient's circumstances and fulfil all the statutory requirements laid down in the bill. Then, and only then, will a doctor be able to prescribe a lethal substance to be self-administered or administer a lethal substance without offending the law. The bill prohibits anyone appointing a relative or agent to make a life-shortening decision on their behalf. The procedure is aimed at ensuring that a competent, terminally-ill adult, who seeks assistance to relieve suffering by hastening death, must make the decision personally, after being informed and having considered the matter. Other safeguards are included in the bill as well.

The point I make here is that honourable members should consider the narrow focus of this bill if they seek to argue that its passage would facilitate involuntary euthanasia. It would not. The bill specifically provides immunities against civil or criminal action for those who follow the step-by-step careful procedures of the legislation. However, the full letter of the law will continue to apply to anyone who takes the life of another or who attempts to take a life in all other circumstances. The laws in relation to homicide apply now and will continue to apply.

What this bill asks members to do is to amend Territory law to provide that a medical practitioner, who responds to the request of a dying but competent individual for the supply of a lethal drug or assistance to administer such a drug, shall not be prosecuted for murder or manslaughter if the procedures of the bill
are followed. The focus of this legislation is to give those who suffer the right to choose a death with dignity, to bring to an end the torture many endure on their death-bed, and for that to be done legally without fear of prosecution for those doctors or nurses who may assist a patient in this desire.

Despite modern technological advances and the most advanced palliative care, sadly some terminally ill patients suffer a gruesome death. Even with the best medical care, some people will always demand a speedier end, and that is understandable when you contemplate some of the most dreaded forms of death. As an example, I will now read into the record some advice provided to me by a palliative care specialist. I quote:

Pain, particularly that due to infiltration by cancer of extremely sensitive nerve-rich areas, such as the brain, head and neck, pelvis and spine, is commonly episodic and excruciating, aggravated by movement, and may be likened to a dental drill on an unanaesthetised tooth nerve.

As such, it is not capable of adequate control by palliative medicine. 5-10% of cancer pain may be of this type and can only be 'palliated' by producing a prolonged unconsciousness, coma or 'pharmacological oblivion'. This may last for days until death occurs by dehydration and circulatory collapse or retention of bronchial secretions ('the death rattle') pneumonia and pulmonary collapse.

Add to the pain intractable vomiting, gastrointestinal haemorrhage, air starvation and massive loss of weight and it is easy to picture that this is not a dignified process.

If this bill is not passed, honourable members can be certain that they will be condemning some unfortunates in our community to death by symptoms of this nature, referred to by some as 'natural death' and by others as 'slow euthanasia'. A recent 2-year study of terminally-ill patients at Daw House Hospice in South Australia has shown that 6% of patients asked medical staff for a speedier end. The report on that study describes these requests as 'spontaneous expressions' by the patients. Of a total of 331 in the study period 1991-93, 21 people in all asked their carers: 'Please, do something now'. They sought voluntary euthanasia.

We are an odd society, at least in relation to this issue. In some circumstances, life can be shortened for the terminally ill. They can refuse medical treatment, operations, life support systems and resuscitation and thereby bring about an earlier death. Our Natural Death Act even allows a competent adult to designate that others can make a decision to accelerate death for them by switching off life support equipment. Thus, Northern Territory law dictates to the patient who is dying in agony: end your life if you like, but you will have to do it slowly and no one can legally help you. We can legally let them die, but it is illegal to help them to die. Thus far, we have not had the compassion required to provide them with relief even when they have asked for it.

All law is, in effect, the codification of the will of the people and, when there are variances between the law and what most people want, as there is on this issue, it is our duty to change the law. It is for this reason, and for the unfortunate who must face the prospect of dying a so-called 'natural death' in suffering and distress, that this bill is before members today. It is about the right of competent, terminally-ill adults to make a considered choice about when and how they die should their suffering become too great. I am not claiming that death is inevitably a painful or distressing experience. To the extent that the living can know, for many it is not. But we also know that regretfully, for some, it is unbearable.
I do not expect passage of this bill will lead to numerous requests for its use. As the hospice study from South Australia indicates, a small number of the terminally ill ask for help to die. The will to live is probably the strongest driving force of all. Patients will hang on while their quality of life is acceptable but, if the pain and distress of terminal illness become insufferable, they should have the right to die at the time of their choosing.

The President of the Australian Medical Association, Dr Brendan Nelson, has said it is possible that, with the continuing spread of knowledge about modern palliative care, more terminally-ill patients will remain comfortable and that requests to hasten death could diminish. Obviously, we all hope this is so. However, it does not alter the need to change the law because it is acknowledged that, for some patients, there remain symptoms that are beyond the reach of even the best quality palliative care. Most people simply want the reassurance that, if their situation becomes desperate, they can obtain help to die. Even the worst afflicted will delay the decision as late as they can - until their life becomes unbearable. If you have watched the last minutes of an agonising death - and it takes courage not to turn away - then you will support this legislation to afford relief to the suffering who ask for it.

Since announcing my intention to introduce this bill, I have spoken with a doctor who described how and why he killed his suffering mother in the presence of his father. I have also a signed letter from a Darwin woman who was forced to kill her father after a long battle with a particularly insidious cancer. During the last 6 months, the father was slowly dying of starvation and was in such a wretched state of pain that he and the family prayed constantly for him to die. This woman was very close to her father and, in the end, she could no longer stand to watch the man she loved, who gave her life, continue to suffer so horribly and she personally fulfilled his wish to die. She told me her only regret is that she did not do it earlier. At least one similar experience was relayed over Talkback radio a couple of weeks ago.

If we, as legislators, wring our hands and turn our backs, we are compelling suffering citizens to beg their loved ones to take the law into their own hands by whatever means they have available because current laws forbid the medical profession to do what is humane. The frightening prospect of an inexperienced family member botching an assisted suicide, and its effect on the family thereafter, is an awful thing to contemplate.

The Australian Medical Association's position is that, as a matter of policy, it does not support the act of a doctor intentionally ending life. Nevertheless, the AMA President has admitted publicly to himself taking life with patient consent in 2 exceptional circumstances, and he suggests that most doctors have faced similar situations. The problem for patients who wish to end their lives is that they cannot be assured of finding a sympathetic doctor. If they could, there would be no cases where ordinary, unqualified Australians were driven to take a life themselves because the doctor refused to help.

In July 1994, the Medical Journal of Australia published the results of a survey of New South Wales and ACT doctors who had been asked a series of questions about terminally-ill patients and euthanasia. 1268 doctors responded. Almost half confirmed that they had been asked by a suffering patient to hasten death. Only 28% complied with the patient request. Of those who refused, 29% said their decision was based in part on legal issues, 19% said illegality was the primary reason and 3% based their decision not to help wholly on the illegality of the act. It is therefore clear that the law as it stands actively ensures that many doctors will not intervene to assist patients to end their suffering because of fear of legal action. And yet, in answer to the question, 'If active voluntary euthanasia were legal, and an incurably ill patient asked you to hasten death, would you comply with the request?', 50% of doctors said that they would comply.
The fact is that AMA policy officially opposes voluntary euthanasia but some doctors admit to practising it and some declare they would not practise it even if the law permitted. There is no surety here for the terminally-ill patient who wants a doctor who is prepared to comply with their wishes and so control the timing of their death.

Dr Nelson and the Territory President of the AMA may have faith in the AMA's policy, but it is a misplaced faith because, in effect, the policy often ignores the patient's desire and contributes to prolonged and unnecessary suffering. It is clear from the research published in the Medical Journal of Australia that, even if the law were changed, some doctors would still not comply with their patient's requests, for reasons no doubt including their personal religious beliefs and their perception of medical ethics. Research, statements on the public record by doctors and anecdotal knowledge within the community all confirm that, when deemed appropriate, some doctors actively terminate life and some do not. Those who do currently run a legal risk, and one of the intentions of this bill is to protect members of the medical profession by providing a solution to the dilemma they face. It protects those who are prepared to act to fulfil a patient's desire. It also enshrines the right of doctors and any other medical staff to refuse to participate in fulfilling the request of a patient. This is an important provision to ensure that influence is not brought to bear on individuals to act contrary to their beliefs.

I wish to turn now to the question of opposition to the concept based on religious belief. I appreciate that those who object on these grounds hold those beliefs sincerely, but the question which must be asked is whether those beliefs should be forced on others. Let me quote from a letter I received recently from a church leader 'Laws are made for the common good and at times individuals must suffer for the greater good of others'. I accept that, if a government makes a decision to send troops to war, it is dictating that some will suffer for the greater good of others, but what 'greater good of others' is achieved by insisting that unrelievable suffering by an individual must not be stopped even if they want to die? To accept the church argument, you have to believe that the rest of us are somehow enhanced or benefit from the suffering we witness when a loved one dies.

I am not a student of religious theory. Perhaps it could be argued that having witnessed great suffering makes one a better person and therefore society needs people to suffer so the rest of us can learn from it. My response to that is, even if voluntary euthanasia were legal the world over, there remains more than enough human suffering to draw lessons from. What I find even more chilling is the attitude of a priest who wrote to me. He said:

During the last 36 years I have been privileged as a priest to share the secrets of the hearts of many sick, suffering, dying people.

He went on:

I am convinced that, no matter what words the pain provided, their hearts were saying: 'Do not kill me'. To take away my life, even if I ask you to, would be to deal me the supreme indignity.

That is a statement from a man who can justify in his mind any suffering no matter how great. I wonder if a person who holds those views could watch an animal suffer an agonising death without intervening.

It would be easy to conclude that some strongly religious people are more afraid of death than others in the community. I have found nothing in the religious arguments, which demand the imposition of a belief on others, to alter my resolve to work towards ensuring that the wishes of patients are sacrosanct. Neither the doctor, the family, or the church should be allowed to override the patient in regard to the right to die.
If you believe that only God can give life and only God can take it, actions available under this bill are not for you. I aim simply to give those who desire a choice the right to make it. It is not appropriate that law on voluntary euthanasia should enshrine a particular religious point of view. Public policies should be based on respect for personal autonomy in order that people who approach questions of life from different moral and religious perspectives are allowed to live their lives in accordance with their values and beliefs so long as the practice of those values and beliefs does not adversely affect others. An individual should be allowed to retain personal autonomy over end-of-life decisions.

From support I have received, and the public debate so far, I am certain that many who consider themselves Catholic, Protestant or whatever also support the concept of voluntary euthanasia. For example, the *Sunday Territorian* asked the question: 'Should euthanasia be legal in the Northern Territory?' On 12 February, it reported that 576 people had registered a vote with 80% voting yes. On 15 February, *The Australian* published findings by the respected pollster *Newspoll* which showed 81% in favour from a nationwide sample of 1200 people. The question asked by *Newspoll* was this:

Thinking about euthanasia, where a doctor complies with the wishes of a dying patient to have his or her life ended, are you in favour or against changing the law to allow doctors to comply with the wishes of the dying patient to end his or her life?

From this statistically sound sample, 8 in 10 agreed they would support a law to allow voluntary euthanasia.

I think we must accept that some respondents who favoured euthanasia in both polls would be practising Christians or members of other faiths. However, even if all the church-going population opposed this legislation, that would not be sufficient cause for members of this Assembly to reject this bill. We in this Chamber are representatives of the people, all of the people. We each have a responsibility as the representative in this Chamber of constituents who did not vote for us - as well as those who did. It is our duty to accept that this is so. It is our duty, in this debate, to remember that our constituents include families like those I spoke of earlier who were driven through love and compassion to defy the law. Our constituents also include the terminally ill who increasingly, through the media and correspondence, are demanding the passage of this bill. It is not our duty to turn our backs on them, nor to deny them a choice in law.

Let me make it clear: this bill is about personal choice. There is no compulsion in this legislation. There is no requirement that every terminally-ill patient must consider whether or not to hasten their death. But we know that some do want that choice. The question for those who oppose this bill is: why should that choice be denied? If they cannot address this question, then I fear that anything they may have to say attempts to impose their personal beliefs on others, beliefs that would continue to compel some of our citizens to die in agony, and force loved ones, through compassion, to take the law into their own hands. I ask members to consider this question: why should this parliament deny adult patients, who are mentally competent and in the last stages of terminal illness, the choice of bringing an end to their suffering?

Some have argued that the proposed measure will open the door to the widespread use of euthanasia without patient consent. Surely that is an absurd argument, one that is strong on rhetoric and short on reason. The notion that supporting this bill would somehow lead to sanctioning the acceleration of death against the wishes of a patient is, in my opinion, quite implausible. Such action would contradict the very basis on which voluntary euthanasia is being proposed - the principle of respect for human freedom and
autonomy. The claim that it will lead inevitably to non-voluntary euthanasia, as was practised in the politically corrupt Germany in the 1930s and 1940s, has long been a major tactic of those opposed to voluntary euthanasia. This scare is repeated by opponents at every opportunity in the world-wide euthanasia debate. It is, in my view, an obscenity to associate this practical legislation, which has popular support, with the shadow of the Third Reich. It is also an insult to Australian doctors to seek to pretend that the profession would be associated with such a wicked scenario. This is a classic technique for creating fear in order to stop social change, and it is unworthy of members of this House.

I urge those who are inclined to accept the so-called 'slippery slope' proposition, that voluntary euthanasia opens the door for all forms of euthanasia, to read the bill with an open mind and then to examine their consciences. After a fair appraisal of the legislation, they will know that this bill does no more than formalise and decriminalise a practice which occurs occasionally now but a practice for which some patients regrettably cannot find sympathetic doctors prepared to risk their careers and liberty. I urge the critics to ask themselves if they believe they have the right to limit the options of a terminally-ill, adult patient who is suffering great pain and distress. I ask my colleagues in this House if they believe it is truly their representative duty to continue to permit an anachronistic situation to exist that compels some of our citizens to endure great pain before they die.

Let me summarise what the bill is not about. It does not provide carte blanche for euthanasia. It contemplates no externally-imposed end-of-life decisions for the aged, the disabled or for anyone else. In simple language, it provides mentally-competent, terminally-ill patients with the right to choose to shorten their agony peacefully and with dignity. It is restricted solely to adult patients who are terminally ill and able to make a judgment for themselves after advice from their doctor. It is a matter of choice. As one caller to ABC Radio Talkback said, the choice is not so much a 'death versus life' decision but a choice between 'dying with some sort of dignity and dying an excruciating hell'.

Some may view passage of this bill as revolutionary social change. It is no such thing. Enactment will confirm that we are a mature society acknowledging the rights of mature individuals. As legislators, we have the opportunity to face up to the dilemma that has baffled politicians in many other jurisdictions for years. As far as I am aware, only the state of Oregon in the United States and The Netherlands have laws relating to euthanasia on their statute books. A recent referendum in Oregon effectively approved a law allowing voluntary euthanasia, but currently a court injunction is delaying its implementation. In The Netherlands, euthanasia is illegal but, through convoluted legislative provisions, the practice is common. To my mind, what is done there is unacceptable. Doctors actually break the law and then submit reports to the police prosecutor who gives them discretionary immunity provided the paperwork is in order. The situation there is not a model we should follow, nor should we even attempt to compare this bill with what prevails in The Netherlands. What is done there is not proposed for the Northern Territory, thus there is no gain in this debate in alleging that the bill before our Assembly is comparable with the Dutch situation. It is not.

I anticipated that my announcement on 1 February would draw trenchant criticism from some quarters, including Right to Life groups in the states who have long stood against any termination of pregnancies as well as any form of euthanasia. However, I was surprised to learn, in the early stages of the public debate, that one leading opponent of this bill in the Territory considers that this Assembly is not competent to decide this matter. A southern politician made this same assertion during a television debate with me. They were short on logical argument and therefore they attacked the competence of this legislature. As far as I am concerned, Territorians have every right to decide this matter and any other
matter within our legal jurisdiction. It is interesting to consider the probability that, on the passage of this bill, opponents of this calibre might seek to have the Commonwealth veto the law under the reserve powers that Canberra still holds through the Northern Territory (Self-Government) Act. The in-principle support for this bill by the federal Minister for Human Services and Health makes that unlikely, but it has been interesting to consider to what lengths opponents driven by an emotional commitment might go to deny a right which so many desire.

The evidence is that the overwhelming majority of Territorians and indeed Australians support this measure. I ask honourable members to consider these words from John Stuart Mill's famous essay On Liberty:

The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others ... over himself, over his own body and mind, the individual is sovereign.

Members would do well to consider these powerful words because this bill gives individuals the sovereignty to decide for themselves.

Let me summarise. This Assembly has before it the challenge to decriminalise what occurs already in secret. Citizens dying in agony who cry out for help do not all receive assistance from sympathetic doctors. Those doctors who assist do so at some legal risk, and others refuse assistance for fear of prosecution. In some cases, family members resort to manslaughter, or murder in the minds of some, to help a loved one. As it stands, the law forces some of our citizens to assist in suicide. These circumstances do exist. Surely they should not be part of a civilised humane society? Surely, it would be far better to guarantee the choice of a humane and dignified end for those who desire it and to free medical carers from the fear of legal sanction? This reform is long overdue. It has support from professors of medicine and ethics, surgeons, doctors and palliative care experts. It has support from experienced nurses and others who care for the dying. Eight out of 10 Australians, many of whom I am sure would consider themselves to be Christians, want voluntary euthanasia decriminalised.

This bill is not about compromising anyone's religious beliefs, humanitarian values or the ethics of the medical profession. What it does, and all it does, is give unfortunate individuals, and only those individuals, the right to choose a more humane end to their life if they are terminally ill, near death and find the pain and stress beyond their capacity to endure. Those who oppose it should not pretend that it is the first step down the so-called 'slippery slope' when plainly it is not. The issue before us is too important to tilt at windmills that do not exist.

I ask those members who intend to oppose the bill to be honestly critical of the bill itself and not seek to pretend that it opens the door to the practice of widespread state-sanctioned death in our hospitals. The major concern of the medical profession is patient care. In some cases, care means the option of final release and doctors admit that this is so. I am certain the AMA will finally agree with me that, when this bill becomes law, doctors will abide by its provisions in the best spirit of the medical tradition.

No one should be overawed by the thought that this bill is breaking new ground. It is not a step into the unknown. It merely gives sanction, with due safeguards, to a practice which occurs now behind closed doors and a practice which most in the community condone. Yet all of those who participate in this practice - the dying individual, a doctor or nurse who takes some action to accelerate the death, or a relative who helps a loved one to die - may offend under the Criminal Code. That is my reading of the Criminal Code. Section 169 states that anyone who attempts to kill themselves is guilty of a crime and is
liable to a penalty of one year in jail. Section 168 provides a penalty of life imprisonment for anyone who aids another to kill herself or himself. This penalty can apply even to a person who gives verbal advice as well as those who assist a person to commit suicide. Thus, we do have a law on voluntary euthanasia - we prohibit it.

I seek members' support to change a law that is demonstrably out of step with what our constituents desire. It is our job as legislators to face up to the need for change, to debate that need and then to stand up and be counted. I do not ask members to lead public opinion; I urge them to catch up with it. And I invite them to consider these further words from the essay *On Liberty*:

> The only freedom which deserves the name is that of pursuing our own good in our own way, so long as we do not attempt to deprive others of theirs, or impede their efforts to obtain it.

Mr Speaker, I commend the bill to the House.

Debate adjourned.

Extract from the *Parliamentary Record* 22 February 1995. *Last updated:*
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