The committee convened at 3.30 pm.

INQUIRY INTO VOLUNTARY ASSISTED DYING
Community Consultation Drop-in Session

Mr CHAIR: First of all, I want to say thank you for taking the time to come and have a chat with us. You never know when we go somewhere whether we will be talking to one person, or 100 or nobody, but fortunately everywhere we have gone it has been really great. Everybody has been very open and talking to us about a range of things that have been really informative.

My name is Tanzil. I am one of the 25 members of the parliament, and my four colleagues—we are four of the five members of the Legal and Constitutional Affairs Committee of the parliament. We were asked by the government to look into this report and talk about voluntary assisted dying, which we will do in a tick. But before we do anything else.

Ms JAMES: Is that the report that came out more than 12 months ago?

Mr CHAIR: Yes, that is right, the independent expert panel report. Before we get into the nitty-gritty, I might just let everyone introduce themselves, so we all know who is who.

Mr KERLE: My name is Matthew Kerle. I am the Member for Blain which is a seat up in Palmerston, near Darwin.

Mrs CARLSON: I am Oly Carlson, the Member for Wanguri in the northern suburbs next door to the Casuarina Shopping Centre and near RDH.

Mr KINROSS: I am Chris, and I work over at the Tennant Creek Library (inaudible).

Mr CHAIR: Fantastic.

Mr YOUNG: My name is Dheran Young. I am the Member for Daly. That seat takes in the communities of Wagait Beach, Dundee, Berry Springs, Pine Creek out to Daly River and Wadeye.

Ms BROCKIE: I am Alba Brockie. I have a lot of hats.

Mr CHAIR: Pick one.

Ms BROCKIE: I am kind of coming because we came to this other one and we were wondering what happened to that and where we are along the process.

Mr CHAIR: We will tell you all you want to know.

Ms JAMES: My name is Amy James, and I am the woman with the Disability Advisory Committee in the community.

Mr CHAIR: It is good to have everyone here. Thank you to everyone for taking the time. We are trying to talk to as many people as we can, so we are grateful whenever anyone makes the time whether they are a mayor or local constituents or an aged-care centre or whoever wants to make time to talk to us about these issues. What I might do—is there somebody else going to join?

Funny story, we had somebody come to us in Alice Springs who sat there for a while before they said, ‘I did not realise this was about dying; I thought this was about dyeing wool.’ We were like, ‘Oh no’. He told us the story about he had knitted a jumper for Johnny Cash once after dyeing wool. Then he said, This was very interesting, but I am going to leave now’.

Ms JAMES: I would have thought that this would be one market. Dying affects everybody, so if you wandered into the wrong room.

Mr CHAIR: It caught us off guard as well. We thought he was joking with for a second but, no, he was deadly serious.

Mr KERLE: He thought it was about helping him dye wool.

Mr CHAIR: It turns out not so much. We are here today to talk about voluntary assisted dying, or some people call it V-A-D, or VAD. What that is about in general, as I am sure you will know, but just to make sure we are on the same page—it is about somebody getting a prescribed substance to help them when they are terminally ill, to pass on, when they are an eligible person, to give them choice essentially for medical support to end their life in a manner and time of their choosing.

We know that talking about death and dying can be very difficult for a lot of people, and we always say this at the beginning of every conversation with anyone: if at any time you feel uncomfortable or upset or want to take a break, just let us know and then we can stop, and take a break. Our parliamentary support service team is here. We have Caroline in the corner, Katie and Georgia. They have access to resources, and they also help us out in that regard as well.

The other thing we will just mention is that we are recording this meeting. The reason we are recording all the meetings is so that we can use the evidence as part of the report that we are going to be writing. If there is anything that you want to say that you want kept private, just let us know, and then we will keep that part private and confidential. Again, sometimes people tell us stories about medical conditions or personal stories, or their experiences with voluntary assisted dying in some form. So just let us know if you want anything kept private.

Ms JAMES: We did give our names earlier which I am okay with, but I assume that it is kind of not, there is such a small number of us here, that you are not saying those people here at that session and these things were said, or?

Mr CHAIR: At the moment that is the standard that we have. Each of our sessions at the moment, we have identified by name, the participants that are there and there were attributing statements to individual people.

Ms JAMES: Okay.

Mr CHAIR: But then, those transcripts become public as part of all the transcripts that become public, unless there is something that we choose to redact. On occasion somebody has said, 'I would rather that detail was kept out', and that is the part that members were considering.

Ms BROCKIE: I have certainly been there where people tell stories about, 'My dad … it was like this', and you probably do not want that published.

Mr CHAIR: Some people do not …

Mrs CARLSON: You can say which parts.

Ms BROCKIE: I understand that. What you are saying now—they will write down that you said it. You can tell them now that you do not want your name with it, if you want it just to be said and they do not know who said it. What do you want to do, do you want to keep your name with what you say?

Ms JAMES: I will keep my name.

Mrs CARLSON: There might be just sections that you also want to be kept off the record. You can tell us but then straight away just tell us that bit needs to be redacted.

Mr CHAIR: Yes, it is good to be clear about all this at the beginning.

Ms BROCKIE: Yes, because I do not mind that it will be recorded that I came, but I may not want everything public, that is the point of it. It may be private stuff.

Mr CHAIR: Absolutely fine. Keep us informed as you are talking, if there is a bit you do not want included, your name, or in totality—whatever it might be, let us know.

Ms BROCKIE: I did come here with other people's stories, that I have permission from any of them to have them linked with a name. I might say, 'I am aware of'.

Mr CHAIR: That is totally fine, absolutely. Let us get you up to speed everyone on, given that you were involved in this last time as well. I will tell you roughly what is going on here. To jump back one step further, in 1995 the Northern Territory passed a voluntary euthanasia law, which was the first place in the country to have a law like that. That law was only active for one year, before the federal government intervened to overturn that law and decided that territories could not make laws about euthanasia—about what we now commonly refer to as voluntary assisted dying.

Twenty-odd-years later, in 2022, the federal government decided that now territories could make laws in that space. In the meantime, between 20117 and now, every state and territory in Australia has made a law on voluntary assisted dying, except the Northern Territory. Last year, an independent expert advisory group, made up of a range of different people, professionals, doctors, lawyers, healthcare workers and community spokespeople and all sorts of people—but not the government itself—were asked to produce this report on how the Northern Territory maybe could move forward on voluntary assisted dying as well.

We were asked, as a group of parliamentarians, who are the Legal and Constitutional Affairs Committee, to look at this report and see how it might work. We were also asked to do a few specific things. We were asked to go out to remote communities to see how those communities felt about this. There was the suggestion that not enough remote communities had been consulted about this issue. That is why over the last month of August, we have been doing the best we can in a month to get to as many places as we can. Some places we have spoken to a council, to everyday people, to a health organisation, in an aged-care setting, or whoever has been willing to talk us or who staff have been able to help organise for us to speak with. We obviously could not go everywhere and we have not been able to speak to everyone, but to as many people as we can out bush.

The third and fourth parts of what the terms of reference asked us to do, was to think about how VAD works everywhere else and how it might work in the Northern Territory, especially given that the Northern Territory is different from the rest of the country, in terms of disease, doctors, population, geography, the number of Indigenous people and all those factors. The last part of what we were asked to do, which is new and different from this report or any other report, is that if we thought that there was probably support for a law on VAD, for us to provide some drafting instructions—not an actual Bill, but instructions for what we think should be in a Bill, if there was going to be a voluntary assisted dying law.

That is a lot to do in a short space of time, as you can appreciate, and we are sort of multitasking everything. We did the first part of what we were asked to do, which was to write a consultation paper, which is this summarised plus our thoughts about what we think we might want to test. From there, we also produced an interim report, which came out in July, which was mostly about what our plan was, where we going, what sort of things we wanted to ask about and what the timeline was.

All things going well, at the end of this week we will finish the process of collecting all our submissions, the written submissions that people from around the Territory have been giving us, as well as we will finish these processes of consultations that we have been doing. This is our last week, today and tomorrow we are in Tennant Creek, and we have been in half a dozen or dozen other places around the Territory. We will then start putting it all together from next week. By the end of September, we will report back to the Attorney-General—the law minister. It is then up to the government to decide what they want to do with our report. We should be clear that we are not here to make the law. We are here to write a report and advise the government on that basis and then they will decide what happens next.

One thing we know is that VAD, voluntary assisted dying, does not just happen in a vacuum by itself. We know that it affects and intersects with other things like the healthcare system, the aged care system and palliative care, like end-of-life care. So, we are keen to find out everywhere we go, how those things are going in the place that you are at right now. The health department told us when they spoke to us that if they wanted a VAD service it would require more resources and time and money. We want to make sure that if we recommend something, we recommend something sensible that will give Territorians a choice but also that we do not just recommend something that is impossible and will not happen in reality.

Ms BROCKIE: I do not know how far you have been in the Barkly, but I interact with a lot of bush people, and one of the fears that comes up once you explain what has happened is people say, ‘But the government has no money’. I think the point they are making is that they will knock us off because we are costing money.

Mr KERLE: Not like, ‘How can we spend money on that when we do not …’

Ms BROCKIE: The government will save costs because looking after people is expensive, and we will get knocked off because it is the cheap way to handle the system.

Mr KERLE: We have encountered a lot of healthcare hesitancy in different flavours.

Ms BROCKIE: Huge amounts of it. People already think you go to hospital to die or you definitely go to aged care to die, and nobody wants to go there, because—not going there to die, but you will get killed by going there basically. The outcome of being there is that you die because that is the point of your life that you are at, and it happens. But I then think the way people have understood it is that if the government allows people to be killed off, then they would do it as a money-saving technique.

Mr KERLE: I am glad you said that and appreciate it because that can go in our report and inform the government that while they are implementing—if we recommend as a committee in our report that VAD is implemented and then there is a Bill and if that passes, there is a period of time before the first person can actually use it. We probably will need to have some sort of education campaign, which would look differently depending on whether you are at community versus an urban setting. In an urban setting, it would be more about how to access the service whereas in a remote community it might be more like …

Ms BROCKIE: That the service exists.

Mr KERLE: Well, just dealing with some misinformation and trying to figure out how it would look. It is a choice thing, and no-one will make you do it. So, if you hear about it you can say no thanks.

Ms BROCKIE: You can say no thanks at the start.

Mr KERLE: No-one will make you use it.

Mr CHAIR: Let us just stop back a step and maybe hear from all three of you. Do you want to tell us basically how you feel about it, anything you know about it and any concerns or questions you might have? Do you want to start with that?

Ms BROCKIE: You can talk just for yourself, or you can talk as an advocate.

Ms JAMES: I can talk both as an advocate with a disability and myself.

Mr CHAIR: That would be great.

Ms BROCKIE: So, what do you think about the idea of voluntary assisted dying?

Ms JAMES: I think it is really important, yeah.

Ms BROCKIE: Do you want to tell this group why people who you have talked to think it is important?

Ms JAMES: It is like education and learning all this stuff.

Mr CHAIR: Do you have any concerns about it? Are you worried about anything?

Ms JAMES: No.

Mr CHAIR: Why do you think it is a good idea?

Ms JAMES: Because it is helping people with what it is about and learning.

Ms BROCKIE: The education part, but what about the bit where you get to choose, ‘I do not want to do my life anymore, and I would like to take some medicine so I can die’. What do people think about that?

Mr CHAIR: If you are very, very sick, not just anyone.

Ms BROCKIE: Yes, that is true. You cannot just choose to finish. You cannot just get to say, ‘Today is a crappy day; I think I will finish.’ You have to be in hospital, and there has to be doctors. We went through all these ones.

Mr KERLE: You have to be sick and so sick you that you are going to die, and you will be in a lot of pain the whole time.

Ms JAMES: It is up to them.

Mr CHAIR: Choice, yes.

Ms BROCKIE: I think that is the point, wasn't it? I am sorry, I support Amy for a lot of things. We did lots of communications; she sits on a national living with Disability Advisory Board and there were lots of people who were already in states and territories where it was available, except for you. People liked to have the choice.

Ms JAMES: Yes. It is their life too.

Mr CHAIR: Where this report is up to, the short answer to your question was stuck. We have been asked to look at it and move things forward. The direction that it goes in depends on what people like Amy and you all have to say.

Chris, how do you feel about all this?

Mr KINROSS: A couple of things. I have a friend who has a mother-in-law that went overseas to one of the Scandinavian countries, I assume it is Switzerland. They went over and completed their voluntary assisted dying over there, accompanied by their partner and children. They went over there because it was not available in Australia. I assume that all states currently do not have that in effect?

Mr CHAIR: Every state and territory, except the NT, now does have a version of this that is working. How long ago …

Mr KINROSS: It was not that long ago, I think it was last year. I assume whatever was happening where they lived was not available enough.

Mr CHAIR: Do you happen to know where they lived, by any chance?

Mr KINROSS: It was in Victoria. I do not have a lot of details, it is second-hand, but it was a big deal to have to go over and not be amongst their loved ones. Even though the partner and the kids were over there, they both had a kind of fractured relationship, but they were both there for the partner and the mother. They did not have the supports around them, so it was quite a traumatic experience, I think, for everyone involved, not just because of the person passing away but all the logistics of it happening somewhere they were not familiar with and all that. The way it was done, they said, it was very respectful and well done, just that part of it.

Mr CHAIR: Do you recall if that person was terminally ill?

Mr KINROSS: I believe so, I believe they were in pain, but I could not tell you definitively if that was the case. That is my recollection.

Mr CHAIR: To be clear, the model that is proposed in here, roughly, is sort of the same everywhere around the country, give or take a few tweaks here and there. But it sort of goes like this. If you are 18 and can give consent, you do not have dementia, you are fully able to give informed consent, and you are suffering and terminally ill, you go to a first doctor essentially and say to them, am I a candidate for this.

Ms BROCKIE: Which might be your doctor, or is it only specialist doctors?

Mr CHAIR: No, that could be any doctor at the moment, anyone to start with the first assessment. If they do not agree you can appeal it.

Ms BROCKIE: Basically if they say, You are terminally ill'?

Mr CHAIR: Yes. If that first doctor gives you the go ahead, then there is a waiting period, which is usually nine days—it is five days in some places—and then you go to a second doctor. The second doctor, in some places it is a specialist in the thing you are dying of, or, in some places, it can be a more general thing. If both of those doctors separately sign off on this, then the third stage is that you have to give written consent, and you need some witnesses for that. Those witnesses need to be separate, independent people, not people who are for example beneficiaries under the will.

Ms BROCKIE: They are not going to get your estate.

Mr CHAIR: Yes, stuff like that. If those people all sign off, then the final stage is that an administration team, again usually headed by a doctor, but in some places it could be a nurse practitioner, they are able to help with the administration of a substance intravenously to help you pass on. Or, if you want to self-administer, there are versions where you can take something orally as well. When you take that orally, it could be supervised in some places by a medical practitioner, some places it could be unsupervised, but just a contact person that you nominated helps with that administration and then afterwards returns the leftovers and notifies the authorities and that sort of thing.

That is the sort of rough set up of how it works everywhere. In Switzerland, as you were pointing out—there are a number of other countries that have voluntary assisted dying. Some of them have more permissive rules. Some of them allow you to access VAD in different circumstances than Australia. Like for example, in Australia, nobody with dementia in any state or territory.

Mr KINROSS: I think that has given me the recollection that I am pretty sure it was dementia, and this person had very strong views of that before they started going into dementia, and they were making decisions along the way I believe, in times of clarity, that that is what they wanted to do. I believe that they had some clarity still around it when they were over there.

Mr CHAIR: That makes a ton of sense.

Ms BROCKIE: This is not likely that the Northern Territory is going to that with the discussions we had there.

Mr CHAIR: I would not think so.

Ms BROCKIE: I think that will still be the case for Australians who feel strongly enough about it when they have dementia.

Mr CHAIR: There are some people who would like a more permissive regime. Of course, there are some people who would not like it at all and Australia has more or less settled on a sort of standard and a sort of rough model, and that is roughly what we have explained. What we are trying to work out is how could you provide that in the Northern Territory so that people who want it whether they are in the city or in the bush, or in a remote community or in a homeland for that matter, could access it? But also, we want to make sure that it is not so difficult and so expensive and so impossible that it never actually happens.

We are trying to figure out how to balance that, and it is tough.

Ms BROCKIE: And finding two doctors when you cannot get one. I needed to get old ladies who missed appointments yesterday into the GP. We cannot do it until next week. To find somebody, and then to find someone else in five days or somebody who has that exact training, there is probably only one doctor specialising in this particular thing and they may not even live in the Northern Territory, and then you have to find a second.

Mr CHAIR: That is true. There are definitely limitations. It is not just a straightforward ‘I feel like tomorrow I can do it’. You have to check box off a bunch of things to be able to quality for this. You had a few personal stories that you thought about sharing.

Ms BROCKIE: Other people’s stories.

Mr CHAIR: Do you want to tell us about some of those.?

Ms BROCKIE: I guess this has been the conversation, and the scale is very broad. There are people who are like, ‘Absolutely no way, there is not a chance in hell’, and there are other people who are like, ‘Well, we do it for our dogs so why do we make humans suffer?’ I understand there is that range.

We have someone who lives in this community whose father was in Western Australia and went through the process and the trauma seemed to be with the family, rather than with the individual. They were pretty clear that this is what they wanted, and I have spoken to lots of people who sound like that is the plan, that is what they want for themselves but their kids or their ex-wives or whatever, do not believe in it. So, I would hate to have your job, really. This thing is fraught with if you make a decision, and somebody is going to be unhappy because there is some way where it falls apart.

Mr CHAIR: Not everyone is going to agree, that is true.

Ms BROCKIE: So these are the conversations that you have. Very common is the one that you have just talked about where people say, I want to make the decision that I can go while I have all my marbles’. I am like, well, I do not think the Northern Territory is going to be the first one in Australia to say, ‘You can have voluntary assisted dying once you’ve got dementia’.

Mr CHAIR: The most permissive VAD law, if you want to call it that, in Australia at the moment is the ACT one, which has not actually started. The law has been passed, but nobody has been actually able to use it yet. They will be able to start using it from the end of this year. Probably the area that is most permissive is, in all the other states you essentially have to be dying within 12 months, or in some cases six months for some conditions, before you can qualify for this. In the ACT they decided to not have the 12-month rule so if two doctors can agree that you are definitely dying, it does not matter whether it is dying in 12 months.

Ms BROCKIE: Even if it is going to take the rest of your life, because we have got people here who are dying of their disability, but it may take them years.

Mr CHAIR: So it comes down to a matter of clinical judgement in terms of whether somebody is still terminal and going to pass away, and you can get the medical professionals to agree that someone’s quality of life will be so significantly impaired that it warrants or justifies them being a candidate. That is probably as far as the Australian model has gone anywhere yet and we have not made any hard decisions yet. We are still collecting all this data. We still have hundreds of written submissions as well to go through, and then we will sort of recommend to the government where we reckon the NT is at and what might be able to work.

Mr KINROSS: Is it possible for people from different states and territories to go to another different state or territory?

Mr CHAIR: To some extent, but in almost every place there is a residency requirement.

Ms BROCKIE: Yeah, you have to be a resident, and I know people who have sold up and moved so that they can—because Victoria was first, wasn’t it? So people moved to Victoria.

Mr CHAIR: Correct, in 2017. They are trying to avoid what is called ‘forum shopping’—picking somewhere to do that—by meaning that whatever happens has to happen within that space, but there is some flexibility within that. For example, earlier today we were answering a question about somebody in Queensland and whether or not if they had not lived in Queensland for 12 consecutive months, whether they could still get it there, and you can. You can apply for an exemption, and then if you have a strong connection to that place and you tick all the other criteria then it can still happen in that space.

This report recommends something similar. It basically says that if you have got a strong connection to the NT, if you can evidence that, even if you do not 100% satisfy the residency requirement of having to be here for X period of time, then you should be a candidate for that.

Ms BROCKIE: I think that is the common thing with the bloke who was telling the story about his dad, they had the dad here with them so they could do care towards the end-of-life, but then the father who wanted VAD could not do it here, so they had to go back again. So, it is all this moving around. It is quite common that a person who is ill would end up somewhere where people who are well and could look after them, but you still might need or want to want to end your life.

Mr KERLE: Say we pass it here and all the jurisdictions will have that so then the residency restrictions might be relaxed around the country because there will not be that incentive.

Mr CHAIR: That is possible.

Mr KINROSS: As I understand, it is a very big thing some country men and women want to die on land, but I do not know how possible that is going to be in terms of—a travelling VAD bus.

Mr CHAIR: Let us talk about that.

Mr KINROSS: There will be some people that would probably if they were going to do this, they would want to be able to do it on land. I do not know how popular the idea is just in general with country men and women. Also, I imagine there could be some people very against that, because you are basically going into community and people are dying.

Mr CHAIR: So what you just described, Chris, is a very good summary of a lot of kind of things we have been hearing. The idea of help and choice to finish up well, is something that a lot of people are nodding with. We have been out in remote settings where a lot of the time Indigenous people in particular have said we do not necessarily want an injection or a substance to end our life, but we are okay with other people having that choice. But there is the odd occasion where there have been some people who have said that maybe they would like that choice out in a remote setting, too, not many but there is a little bit of that—we do know there is some of that.

What we want to do is make sure that if we recommend a law for this, that everybody has the option at least, if they want to be part of this, to be part of this. One of the bigger things that you just drew up there about finishing up on country—that comes up a lot. We hear that from a lot of people talking about they would like more help to be able to finish up on country.

Those conversations intersect with aged care, palliative care and the healthcare system generally. We often ask people, 'How is all that going where you live? What is palliative care service like, what is aged-care service like, what are disability services like?' Is there anything about those things in this area that you want to tell us about.

Ms BROCKIE: People are dying off country because they end up in the hospital system, and even people who are coming here, so they are already off country, are getting shipped out and dying in Alice or Adelaide or Darwin or wherever. So that does distress people for sure. But the flip side of that is that if you are the doctor who is in the travelling roadshow ,and you are doctor death, I think that could be a dangerous job to go into a community and be the person who is known as killing somebody, given the repercussions. There is payback. It might be physically dangerous to be the person who has that role.

Mr CHAIR: This report is very much for having a stand-alone model that is separate to the palliative care system or the healthcare system to try and provide a little bit of separation and protection in that regard. We know that is not a bad idea in theory, but in practicality, we also know there are only so many doctors and nurses and we know that maybe only 10 or 20 people a year might take this up in the Northern Territory if it was to be the law. It would be tough to have a completely standalone service.

We are trying to work out how we could provide the opportunity for people to have access to this but not suggest something that is impossible. One of the ways that might happen is the sort of process I described to you before, that is talking with the first doctor and then second doctor. Maybe those are things that could happen using existing doctors and an existing network of healthcare. Then the last part involving administration could maybe involve people that are not living in that same community or who could come in especially from outside, sort of fly-in, fly-out, to help with something like that. At the same time, some people are suggesting that they would not want an outsider or a stranger. It is difficult to balance all of that.

Best guess is that there are about 1,400 doctors in the Northern Territory. Some of them will want to be part of this and some will not. We are thinking about how to provide the opportunity with a regulatory framework to allow people who want to choose to be part of it, to be part of it, and people who do not, to be able to opt out.

That includes doctors, nurses, translators. We had an Aboriginal liaison officer who recently told us that they were not very comfortable translating these subjects. Someone like that should not be forced to do that as part of their job.

We are trying to figure out how this might work. We have not spoken to many people from disability advocacy setup, Amy, so I am mindful that we might be able to get some extra insight from you. You have had some conversations about this at the national level. Is that right?

Ms JAMES: Yes.

Mr CHAIR: What sort of things have you learnt there or that you could share with us about that?

Ms JAMES: A lot.

Mr CHAIR: You have time.

Ms BROCKIE: What do people say they are worried about? To do with the voluntary assisted dying? There was one lady who was worried that the doctors and the people who she was working with, she saw her quality of life as pretty good, but outsiders did not.

Ms JAMES: They did not.

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Mr CHAIR: Sure, there are lots to pick from. Again, we try to make it clear that you must have full mental capacities—you cannot have dementia—in order to be able to opt into this model. At least, as the report stands and the other systems stand, you must be terminally ill. You can have a condition and be very ill but still not be terminal. You might have profound renal problems but not be within a 12-month prognosis of passing away. In that situation, the doctors would not necessarily sign off on this.

Ms BROCKIE: We have seen people with renal issues—which is a good example—where as long as they kept turning up, they are not terminal. But if they stopped going, they are terminal. We see people who are basically doing a voluntary dying anyway, because they have chosen to no longer do the treatment. They want to die on country and go back to country, and that is what they are doing.

Mr CHAIR: Do you know of circumstances like that personally?

Ms BROCKIE: Yes. People make a choice that they do not want this anymore and therefore stop it.

Mr CHAIR: In the circumstances you know about, without naming any names, do you know that people have actually said, ‘No more treatment for me; I am going back.’

Ms BROCKIE: They do not say it; they just leave and go back where there is no treatment.

Mr CHAIR: They go back to a place without treatment, knowing there is no treatment there, because they would rather go back and finish up on country?

Ms BROCKIE: Yes.

Mr CHAIR: You know about those anecdotally or personally?

Ms BROCKIE: Yes. I know some people who have done it, but I also know people who have made that choice and then they get really sick and then come back into the hospital system. Maybe they are choosing for themselves to do it, but other people are saying, ‘Right, that is it; I cannot sit around watching this anymore. You need to get back on your renal.’

Mr CHAIR: Yes, we get that. We know that people would prefer to choose to finish up on country a lot of the time. Sometimes they do not get back in time or sometimes there are things that stop them from being able to get back in time. Do you know of any instances like that?

Ms BROCKIE: Part of it is the system. If you do not have transport, it physically cannot happen for people. Is that what you mean?

Mr CHAIR: Yes.

Ms BROCKIE: This is the part of choosing the right doctors. I am not sure if you are getting many people on the ‘no’ scale in this. Presumably, it is people with an open mind who are coming to the discussion. If you have already said, ‘That is it’, you might not be coming to the discussion. I have certainly had interactions with medical people where I am trying to advocate for a patient who wants to cut things out and the medical system says, ‘No, we just need to keep your pain away. We have ways to stop your pain; that is all we have to do.’ And people are like, ‘No, I just want to go’. Today, she was pulling it out of her arm; she was going.

Ms JAMES: She was like, ‘No. I am going to look after my dog.’ That is what she wanted.

Ms BROCKIE: Yes, she wanted to look after her dog.

Mr KERLE: Was that at the hospital?

Ms BROCKIE: Yes. This is not necessarily a terminally ill, but if you do not sort it now, you will be.

Mr CHAIR: Was this someone who essentially wanted to withdraw from patient care?

Ms BROCKIE: Yes. This is an everyday problem for the hospital. Partly because people do not understand. I have seen people here who have had an infection on their foot. If they had just stuck with their antibiotics, it would have been finished, but they do not. Then you find them in the community with a football size foot and that person is now in a wheelchair because everything inside the foot is so destroyed that the foot cannot work anymore. That is not a terminal illness thing; it is just rejection of a system that does not work for people.

Mr KERLE: The lady you were talking about today, is that an education or understanding issue of, ‘I do not want to be here receiving this treatment in this environment’ and pulling it out is a way of trying to escape from that, or is a positive action of she understands and wants to withdraw from treatment and have it end?

Ms BROCKIE: I suspect it is a cultural safety issue. Sometimes it is really simple like the hospital is freezing and people do not want to be in it. It is not always really complicated. In this case, she has some dementia, and she was worried about her dog, wasn’t she?

Ms JAMES: Yes.

Ms BROCKIE: At least that is what she was verbalising. It may not have been the real fear behind it, but what she was telling people is, ‘I need to go home; my dog is locked in the house.’

Mr KERLE: So that is not really withdrawing from treatment. She is concerned about her dog.

Ms BROCKIE: Yes, but the outcome is she has taken it out of her arm and is leaving. If people have that attitude of, ‘I no longer want this medical support’, when you are terminally ill, the outcome will be that you are making a choice to die basically.

Mr CHAIR: This report and a few of the submissions we have now, including from the Alice Springs Hospital for example, have suggested that they support the idea of a VAD law, but they do not want it to happen on hospital or health premises.

Ms BROCKIE: I think that is the complication, isn’t it? I just explained that the attitude to that centre over there is you go there to die, therefore that somehow becomes when you go there, they kill you, which is not the same thing, but nobody wants to put a foot in there because the outcome will be they will be dead.

Mr CHAIR: So, where would be the place for something like this to happen if somebody wanted it to happen in the future? What do you think?

Ms BROCKIE: Who knows? Do you have to build a separate place, so you go quietly out of town and—you are visiting that house, so you know that you are on palliative care and at some point, you make a choice. In my life, in the early to mid-1990s I had a friend who had lung cancer, knew he was finishing up, wanted to die at home and had been in the local small-town hospital. They were in the circumstance where the nurse could provide morphine for his wife or himself to administer. He had a drug use history, so he knew how to use a syringe, and they just built up—a vial came every day from the nurse, and there was one left. She did one, and there was one for the night. They just built up all the night ones. He had us all round over a period of a week or whatever, and everybody had our final conversations. Then one afternoon they had a beverage together and put the extras in, and that was that. That sounds great to me; if I had to go, that would be suiting me just fine.

Mr CHAIR: We appreciate you sharing that story.

Mr BROCKIE: Obviously, that is dangerous. What if a kid got it? What if that nurse got found out? She would be in deep shit.

Mr CHAIR: Yes, that is right. At the moment we have heard anecdotally from different places stories like that. It is not new; we have had that in the past as well. The whole idea about this is to provide a proper framework and legal protections.

Ms BROCKIE: Yes, it will have to be in a building where people cannot wander in and out. You will have to have a place.

Mr CHAIR: Yes, well it could be a separate building. It could equally be a supervised administration somewhere, but we try to separate out—just so there is no confusion—palliative care, pain relief and the situation you just described there, which we know takes place from time to time, from VAD which is a more specific choice and a specific way of passing.

Ms BROCKIE: And that person would have used it if it was available. I think the thing you are saying about specific places or whatever, one of the problems is that people may not even use it. I think it is about this point of choice, isn't it? You say, 'This is what I want' and then you have it available to you for six months, but you have not used it and may just die.

Mr CHAIR: And that happens.

Ms BROCKIE: So that person cannot be sitting—if we build a nice pretty building somewhere, you cannot have somebody just sitting there for six months deciding whether or not they want someone to push the button or take the pill.

Mr CHAIR: Well, on that point, anyone can withdraw from any of this at any time. You could say, 'I would like VAD' and pass all those points, but then when it comes to the crunch if you have a change of heart for whatever reason, you can always do that. Generally, the way it has worked is not that there is one specific place where this happens. People have it at home, in an aged-care facility or in a hospital depending on what the situation is.

I think it is probably unlikely that we recommend just one standalone place where this could happen. I think it would be more about allowing people for it to happen where they want it to happen and whether or not we could help get the assistance to them, knowing that it probably will not happen every day. We are talking about a small number of people, but if there was somebody who was crook out in a remote setting and they filled all the criteria, could we make it so that a medical team could come to them and help them at the right time?

Ms BROCKIE: To me that sounds great, but there is the potential for risk that the person who is making the choices says, 'Yes. This is what I want', but other people around them do not want it and the person or team who is coming are seen as murderers, basically. I do not know how you get around that in terms of physical safety. I feel like that it is a proper thing that has to be considered. It is not just in the Territory, but in the Territory we have payback systems. So, it is probably high on the list of considerations here.

Mr CHAIR: We had a healthcare worker describe a situation where they had a patient who wanted it, but they knew their family did not want to know about it. The patient was specifically asking the guy, 'Do not tell my family, but can you please arrange this for me?' It is complex.

All I can say to all this is that there will be an 18-month implementation window if a Bill gets passed. If this report goes through and the government wants to work on it and then makes a Bill that gets passed and becomes a law, it would still be another 18 months of figuring all this out. We are not in charge of figuring everything out, but we are in charge of at least drawing attention to things that the government and the Health department might want to think about if they go in this direction.

Ms BROCKIE: The NT was first, but now we are last. I assume that gives you a huge advantage because these things have been in practice, and you can learn from other people's situations.

Mr CHAIR: That is the hope, yes. But the NT is a bit different to everywhere else in terms of geography and demography. That makes it a little challenging.

Ms BROCKIE: But if you can find out other people's disasters, then at least you can try and figure out how to navigate around them.

Mr CHAIR: We are trying here. We know about the odd disaster here and there that we are trying to make sure we do not set ourselves up for.

I am mindful that we are running out of time, and I do not want to keep everyone longer than they are meant to be. Before we wrap up, are there any other questions or queries that we can help with, Amy or Chris?

Mr KINROSS: In my life, I traverse Christian and Buddhist religious spheres. Generally, both are against suicide or voluntary assisted dying for different reasons. I am just saying that there are also people within both spheres that are very much—I guess consider themselves a version of libertarian and that people should have the choice to do what they want.

Mr CHAIR: It is a very helpful contribution. Even people of faith sometimes have different views about this. It is not uniform that it is all yes or all no; there can be shades of grey in this. That is helpful to hear as well. Amy, is there anything you wanted to add?

Ms JAMES: I have a best friend. She was fine. She went out to Papunya, and I have not seen her forever.

Ms BROCKIE: That is a whole different thing. That is a mental health thing for her, I think. She wants to give up life for a different reason. If we could move that problem, it might be different. So that is a different reason for why you have had enough of your life.

Mr CHAIR: This report makes it clear that if you only have a mental health problem but not a terminal illness, then you cannot use VAD. But if you have a mental health problem but then also end up having a terminal illness, then you cannot be stopped from accessing it just because you have a mental illness. It tries to make allowance for that, but it will not allow people with dementia or just a mental illness to be able to access this under these rules they are suggesting.

Ms BROCKIE: That is an important component, isn’t it? If you have a terminal illness, you are likely to end up with a mental health issue.

Mr CHAIR: Very likely, sure. It is often the case. Anyway, we need to wrap things up.

Ms BROCKIE: Thank you for your time.

Mr CHAIR: Thank you for your time. We really appreciate you sharing your stories with us.

Ms BROCKIE: We may cross paths tomorrow because there is an elderly gentleman who wanted to be part of this …

Mr CHAIR: Oh, great.

Ms BROCKIE: … and is now hospitalised.

Mr CHAIR: Oh, not great; sorry.

Ms BROCKIE: I believe you are booked in to see him. No, it is great. It is part of what he wants to do, and I am trying to facilitate it for him.

Mr CHAIR: Wonderful. As you know, we will be around all of tomorrow. We will also …

[Recording stopped.]

The committee concluded.