INQUIRY INTO VOLUNTARY ASSISTED DYING
Old Timers Aged Care Centre

[Recording commenced one minute late.]

Mr CHAIR: I will let the committee members introduce themselves.

Mr KERLE: My name is Matthew Kerle. I am the Member for Blain. I represent three suburbs in Palmerston in the Top End in Darwin.

Mrs CARLSON: My name is Oly Carlson. I am the Member for Wanguri. I am a member of parliament and my area is just next door to the Royal Darwin Hospital, in the suburbs surrounding it.

Mr CHAIR: The three of us are three of the five members of the parliament's Legal and Constitutional Affairs Committee. I am the Chair of that committee. We were asked to do a report into another report, if you like. This report came out. We will talk about that in detail in a tick, just to give you the context.

We are also joined by Georgia Eagleton, Katie Helme and Dr Caroline Williams down the back. They are from the parliament as well and they are here to help support us in the inquiry we are running at the moment.

The first thing to say about today is that we are here to talk about voluntary assisted dying. It is talking about death. It can be upsetting, we know, for a lot of people; it can be difficult. We always say up-front to everybody in the beginning that if anybody wants to take a break or if anybody is feeling uncomfortable or upset, just let us know. We can always stop and take a break. Our parliamentary team also have support services information as well that can assist in that regard. Do not be shy if you want to take break.

The other thing you will notice is all the wires. We are recording this meeting. The reason we are recording it is because we are gathering lots of evidence and testimony to help us with writing the report. If there is anything you say that you do not want on that record, just let us know that you want it kept private. Then we will make sure that stuff is removed from the public testimony that goes out as part of all transcripts, essentially.

Before I start hearing from all of you, just so we are all on the same page, I might just try and set the scene a little bit and explain the background to this meeting. In 1995, 30 years ago, the Northern Territory was the first place in Australia to have a law for euthanasia, as it was called then. It was called the *Rights of the Terminally Ill Act* and it allowed people who were terminally ill to have an assisted death. Then in 1996 the federal government decided that the Territory should not be able to make laws of that nature, so it passed a law stopping that law. The ACT and the Northern Territory were disallowed, as well as the seven other territories of Australia, from making laws in the nature of voluntary assisted dying.

Fast-forward to 2022, at that time the federal government undid it again and now made it so that the ACT and the Northern Territory could make VAD laws. In the meantime states, which have different powers, started making voluntary assisted dying laws. In 2017 Victoria did it first, and now every state and territory in Australia, or the six states and the ACT rather, all have a law of some description to provide for voluntary assisted dying. The Northern Territory now is the only place in the country that does not have one.

We know that voluntary assisted dying has been of interest to a lot of Territorians over a long period of time. Some people are for it and some people are against it, but we do know that there are a lot of people who are interested in it.

The last Labor government made an independent group do this report. This was made up of healthcare practitioners, lawyers, community representatives, the former Administrator—lots of people were involved in it. They produced this report last year and it provided 22 recommendations for how we move forward on voluntary assisted dying. But the last government did not do anything further with it, and the new government that has been elected in the last year also did not want to just move ahead with this report without testing it a bit further.

Through the Attorney-General, the law minister, we got a referral, this committee, to look into this. We were asked to do five things basically. The first thing we were asked to do was to write a consultation paper; look at all of this, summarise it and then put that into the public for people to tell us what they think about it. So we did that, and it is publicly available on the Legal and Constitutional Affairs parliamentary website.

The next thing we were asked to do was to go out bush because it was widely felt that remote communities and Indigenous people, who are obviously a big part of our demography up here, had not really been asked much about how they feel about voluntary assisted dying laws. Since the start of August, we have almost been a travelling circus, flying in and out of communities and asking people in the bush how they feel about the laws as well.

Then the third and fourth parts were to look at what might be a voluntary assisted dying model that works for the Northern Territory and do we need to do anything special or different to accommodate for the Northern Territory's unique circumstances. It is obviously very big with a small population and a large Indigenous population et cetera et cetera.

When all that is checked out, we were instructed to provide drafting instructions to create a Bill. A Bill is not a law; a Bill is something that could become a law.

Our job, to be clear, is not to fix everything. Our job is simply to hear from people and to interrogate this and produce a report back for the parliament's consideration, and that is what we are going to do. So we will report back to the parliament in September and then the government will decide on how it wants to progress with the issue.

We would like to know how you feel about voluntary assisted dying. We would like to know if you have any thoughts or knowledge about this at all or this model. We are happy to explain questions, this is very much a conversation today so we can explain recommendations in here or the model that they are suggesting we might follow if we go in this direction.

We want to start by opening the floor generally. If anybody wants to—you have all popped down today presumably to listen and to contribute. If anybody wants to start by just telling us a bit about how they feel about voluntary assisted dying, it would be a good start.

Can I pick anyone at random?

Mr KERLE: Can everyone say their names for the record?

Mr CHAIR: Yes, we can. We have a list that has gone around. We have written everyone's names down. What might be useful, because we are recording this, is whenever you speak if you could say your name then so that we can catch your name before you speak, just for the record. Is that okay? We might do that instead.

I quite fancy your jumper, so I have decided I have nominated you to speak first. It is a very fetching jumper. Would you care to introduce yourself?

JEANNE: I get embarrassed talking in front of everyone. I agree with voluntary assisted dying because I had an experience with my father who was terminally ill with a nasty cancer. He suffered badly with that pain for a year and all he wanted to do was die. If that was available then—that was in South Australia—he would have done it and I would have agreed and so would my mother.

Mr CHAIR: I did not catch your name.

JEANNE: Sorry; Jeanne Lindsey.

Mr CHAIR: Jeanne, we have got the list and we can put in your name.

We hear stories like that commonly. Do other people have other stories like that, or any other feelings?

RESIDENT 1: Is the proposition here in the Territory much different from other states? As you said, they have their own things. Will they be a lot different?

Mr CHAIR: Yes, I can tell you a bit about that. Broadly speaking, there is now a rough Australian model for how voluntary assisted dying is working. There are some minor differences here and there, but it is broadly similar.

This report agrees with some of the stuff. I think it also deviates from a couple of things. I will tell you the key differences, if you like.

Everywhere in the country it is more or less the case that the proposition is available to people who are over 18; can make their own decisions—do not have dementia, for example, so they are still in a position to give proper consent about everything. They have to be terminally ill. They have to have a condition. They cannot just be ill; they have to be dying. There has to be a prognosis that they will die within a certain period. In most places it is basically 12 months, but in some places it is six months, depending on what the condition is. This report suggests 12 months as well for all conditions.

In the rough steps, if you like, in terms of how it works—going through this diagram model—if you are somebody who is sick, you could refer yourself or you could be referred by someone to a GP. Then you would go to see a medical practitioner—it does not have to be a GP, to be clear. If you can convince that person that you are a viable candidate, if you are going to pass away with a terminal illness and you are suffering et cetera, then they would say, 'Yes, you are a candidate for it'.

Then there is a waiting period, which again varies a little bit from place to place, but is usually five to nine days—nine days in most places.

Then there is a second consultation you have to do with a different doctor. That second person, the coordinating physician, can be a specialist or a generalist. The standard varies a little bit from place to place, but the bottom line is two separate doctors have to be able to sign off and say, 'Yes, you have less than 12 months to live; yes, you are terminally ill; yes, you are able to make a decision.'

Then there is a waiting period again of five to nine days. Then at that point you have to provide written consent for this. You have to consent, and people have to witness that, as you would with a lot of formal documents and decisions.

If you manage to get through all of those phases, then in the last phase an administration team, made up of doctors or nurses or nurse practitioners and so on and so forth, can help people with the taking of an injection, essentially, to help you have a hastened death.

That is roughly the model everywhere. One of the key ways that this report deviates from all of that is in terms of the delivery of all of that. One of the things they have suggested is that we should have a standalone VAD service, separate to the health service, so that the waters do not get muddied. So, you have the healthcare system to look after people; you have the palliative care system which is for end-stage care, as you would know; then you would have VAD, which is a separate thing again.

One of the things we are looking at is, as you are all aware, in the Northern Territory there are limited numbers of doctors, nurses and healthcare practitioners, so we are looking at how viable it is to have a totally separate VAD service. That is partly because we know that in other states and territories—say, Victoria, which has had it the longest—every year nearly 450-odd people have been taking up the option to use VAD out of a population of however many millions they have got down there. Our best guess, estimate, is that maybe in the Northern Territory, if a law was passed at some point in the future, around 20-odd people or less might be candidates for this every year.

That is roughly what it looks like at the moment. Does that answer your question?

RESIDENT 1: Yes, that is an idea.

Mr CHAIR: What else on that? Who else is on the floor?

VERN: Vern Ellis. I am just wondering what the percentage—if you are allowed to tell us—so far is for and against?

Mr CHAIR: Sure. There is no clear answer to that number. This particular report did a study and they estimated that 70%-plus people that they surveyed through their survey thought that there should be some sort of law on VAD. Other studies done by other groups in the past have indicated majority support, sometimes 51%, sometimes 99% or a number in between, but majority support essentially.

Now, all the groups that have done that kind of evaluation, whether it is Go Gentle or whether it is the health services—there is a number of the euthanasia societies—they all get different numbers of support. Meanwhile other groups, like the Australian Christian Lobby, might suggest that they think the number is much lower and there is not majority support.

To be clear, our job is not to survey all the Northern Territory again and to determine what that number is. But our feeling at the moment is that there is more than 51% support and less than 100% support. There is support, potentially, for a legislative solution.

What we are trying to think about is if something was done in this space how could we make it so that it is workable, it is practical, it is affordable, it is safe, it is well regulated et cetera et cetera. We are trying to work that out by asking questions about not just VAD but also about aged care, about palliative care, about interpreters out bush, about telehealth—all these things that affect the health system and care for people who are terminally ill. Does that make sense?

VERN: Thank you.

RESIDENT 2: I would like to know once this Bill is passed will there be changes made? Like we get a change of government and they decide to change something in the Bill, will that happen or will it stand in the Bill?

Mr CHAIR: The short answer to that question is, first of all, there is no guarantee that there will be a law. Our job is to deliver a report. The current government has made a commitment to say they will look at the report and then act on it. They could ignore it completely or they could go on with everything we say; that is up to them.

Let us just say hypothetically everything goes very seamlessly and nobody holds up the process with a delay or anything like that, probably the earliest you would have the Bill in the parliament for everyone to consider would be very late this year or early next year. Then if somehow that Bill got passed, what is standard in this, and pretty much everywhere else across the country, is an 18-month implementation period. So, it would still take at least 18 months after a Bill is passed before the first person could ever use this. All of that falls within the timeframe of the current government's period at the moment, but the government could change its mind. The next government could change its mind as well.

So far what we have seen is that in other places these laws are made and have more of less stuck around once they have been made.

RESIDENT 2: I was concerned about that because you get a change in government, someone does not agree with it, then they make changes …

Mr CHAIR: That is correct.

RESIDENT 2: … when people have already figured out—decided—that, 'Yes, I want to do this', and it might be changed.

Mr CHAIR: I think it is probably—we are trading in hypotheticals that I cannot answer …

RESIDENT 2: Yes, I realise that.

Mr CHAIR: … but I will say that other states and territories have passed the law and the law has stuck around. For example, in ACT they passed the law, but it has not actually come into effect yet, so nobody has been able to actually use it yet. They will, at the end of this year, be able to start implementing and exercising VAD rights in the ACT.

Mr KERLE: I might just add, they are not with us today, but we do have a member of the Labor Party as part of this committee. If the government chooses to pick up our report and make a Bill for the parliament from that, the commitment is that it will be a conscience vote. It is more likely that, it being fairly non-partisan, it would stick around.

Mr CHAIR: Yes, we have five members on this committee. The Member for Nightcliff and the Member for Daly—the Greens member and the Labor member—unfortunately, could not be here today. But we are still here as a quorum for you today.

Neither side of government has chosen to take this on by themselves over a long period of time. The most progress we have seen on this for a long time is now the current government asking this committee, which is made up of three different parties, to look at this issue as best we can.

RESIDENT 1: I was going to ask—you said in Victoria that 450 people took part in this, but you think there is only about 20 people in the Territory. How is it going to be viable if—in Victoria you have the number of people, the population, that could set up this standalone thing …

Mr CHAIR: That is a great question; you should join our committee.

RESIDENT 1: How are they going to be feasible to be standalone people to do that for 20 people? It does not operate—something they can do financially and everything. The Territory could actually lose out. They might say, 'Well, you join another state because it is not viable for 20 people for us to be sitting here', so the Territory will lose out again.

Mr CHAIR: A few things there. First of all, there are restrictions on what can be done across jurisdictional borders. At the moment, the advice we have from legal people, health departments and so on and so forth is that it is not feasible for us to outsource this service to another place; nor is it, for a range of reasons essentially, an appropriate solution. That is the first point.

The second point (inaudible) which is to introduce a new component to the health service introduces a new burden—a new set of costs, a new set of everything. The Health department came and spoke to us as well to explain to us that in their opinion, if we were to have a VAD service, it would require them to have extra people, extra money et cetera et cetera to do something that is completely standalone. We are taking that advice on board now as well because, on the one hand, we have the sense that there may be a majority of people who would like some option to make a choice with voluntary assisted dying; at the same time, there is no point in us recommending a Rolls Royce and then discovering nobody needs anything.

We are trying to weigh up all these considerations at the moment. Part of this is thinking about palliative care and how much of that we have and whether we have enough of that at the moment; aged care, if we can support that well at the moment; and all the things that go between. That is also just in urban centres. It gets even more complicated when thinking about out bush in remote areas. How do you provide access to something to people when you know very few of them may want to take it up? Some might, and we would have to give them the opportunity. We are trying to weigh all those things up at the moment.

What we do know is that there is a number of people who feel that Territorians should generally have the opportunity, at least, to be able to make a choice on voluntary assisted dying. We are trying to test how strong that support is by talking to people in some places where maybe people have not spoken to them before. Does that make sense?

Mr KERLE: I am really keen to hear the thoughts of the people here whether you think VAD is a good thing or whether you have reservations about it. Does anyone—thank you for what you shared before. Is anyone else willing to share their perspective on it?

JEANNE: Can I just interrupt for a moment? Why is it an Australian thing that everything has to be abbreviated? People here talk about VAD. What the hell is that?

Mr KERLE: Voluntary assisted dying.

JEANNE: Yes, but you call it that, and that is what people talk about it. Nine times out of 10 people do not understand what VAD is. Why can you not say the full complement of the name? Australians seem to abbreviate everything and all the people being told 'VAD'—it just does not ring right. It has a name; it is voluntary assisted dying. That is what should be talked about, rather than 'VAD', if that makes any sense to anybody else. I think a lot of people feel that. All these abbreviations, and you have no idea what they are talking about.

Mr CHAIR: Generally speaking—go ahead.

RESIDENT 1: Sorry. I was just going to say it is our age; we are not used to abbreviations.

Mr KERLE: No worries.

Mr CHAIR: We change that; we tend to talk about V-A-D and not say 'VAD' too often, but I think it is late in the day for us.

RESIDENT 1: For most of us.

Mr CHAIR: Yes, that is right; it is fine. We will certainly be mindful to use the full terminology when speaking with older cohorts. I think it is a sensible thing to do.

RESIDENT 1: Yes, I think so. You need to because you are addressing older people; you are not addressing an 18-year-old, a little bit more cluey. You are addressing older people and these abbreviations—they get so many things around; in life, everything is abbreviated. As I said V-A-D or 'VAD', mind you, does not sound right.

Mr CHAIR: Let us talk about voluntary assisted dying in this room today. We would still like to know everybody's thoughts about voluntary assisted dying, generally or more specifically; whatever you might care to share with us. How about you, ma'am?

BEVERLY: Beverly. I am all for it.

Mrs CARLSON: Do you have a story to share?

BEVERLY: That is all I can say: I am all for it.

Mr CHAIR: That is all right; it is good to know. We just want to get a sense of what everyone thinks.

JEANNE: I support it.

BETTY: I support it too.

Mr CHAIR: What was your name?

BETTY: Elizabeth Edwards.

Mr CHAIR: Elizabeth.

RESIDENT 1: Your name is Betty.

BETTY: Well, Betty.

[Multiple people speaking.]

RESIDENT 1: I support it, definitely. At the present moment, no-one has realised that it could happen to us, but it is nice to be able to have that choice in front of us, especially when it started 30 years ago. It was a good idea and then it all went, and it was not good. At the present moment we are all sitting here and we are not in the need, but to know that there is something out there that could help us before we go gaga …

Mr CHAIR: 'Before you go gaga' is an important thing to say …

RESIDENT 1: That is right.

Mr CHAIR: … because the truth is one of the things that is consistent across Australia is that only people who are of sound mind can choose this. Once you are not able to make clear decisions this is no longer available. It is not something in any other state or territory at the moment that you can even forward plan for—for example, in an advance personal plan. You cannot say that if it gets to that stage, like a DNR situation (do not resuscitate) …

RESIDENT 1: No acronyms.

Mr CHAIR: But that is the acronym that is used in the paperwork, so that is why I was using it.

The do not resuscitate orders (DNR orders) (inaudible) advance personal plans. You cannot make that same specification with VAD at the moment anywhere else in the country. These decisions do need to be made by people who are fully cogent at the time to make decisions.

RESIDENT 1: That is why we need to—the country itself needs to know, older people—have that in front of them, so they know that if and when they get to that stage, they have got to be …

Mr CHAIR: Sound of mind.

RESIDENT 1: … sound of mind, so that we know it is there and we know we have to do this before we go gaga.

Unidentified speaker: What does 'gaga' mean?

[Multiple people speaking.]

Unidentified speaker: It is abbreviated, is it? What does it stand for?

Mr CHAIR: (inaudible).

Mrs CARLSON: Sorry; coming back to the model. Just on your point there, though, if this became law and a model is produced, if it is very similar to this one here, one of the steps is you still have to have sound mind to give consent. Unfortunately, it may not work in some instances at those later stages, when dementia sets in and Alzheimer's and stuff like that.

RESIDENT 2: Can I ask something?

Mr CHAIR: Sure.

RESIDENT 2: In that case could you, in your will, state that you want to have voluntary assisted dying?

Mrs CARLSON: I will explain the difference. Your will is actually a legal document acting on your wishes on what is to happen to you and your assets afterwards. But this is something maybe we can take on board, as part of our recommendations, how it is going to work with people who know they want that decision, but later down the track get trapped in that dementia stage. Is it something that we may have to look at with the advance personal plans and how we have to integrate it into there possibly?

RESIDENT 2: That is very important.

Unidentified speaker: People have already agreed.

Mrs CARLSON: Yes, unfortunately one of the steps is consent, so how do we write that consent in there?

RESIDENT 3: Excuse me for asking and excuse me for turning up late, but what are we talking about, please?

Mr CHAIR: Sure.

RESIDENT 3: End-of-life decision or …

Mr CHAIR: We are talking very specifically about voluntary assisted dying and we are talking about the report that was done last year and whether or not the Northern Territory should have a voluntary assisted dying law, how do you feel about that—if you have any reservations about it or support for it. We are here from the parliament as members of the Legal and Constitutional Affairs Committee to report back to the parliament about how this issue might go forward in the Northern Territory. Does that clear it up?

RESIDENT 3: It does, yes. Excuse my approach, but I came here thinking, because I do hand spinning and hand knitting, I thought we were talking about dyeing wool from sheep.

Mr CHAIR: It is okay.

RESIDENT 3: I got a message on the phone from Martha(?).

Back in 1993 I had the occasion of meeting the late Johnny Cash. I presented him with a jumper. I not only dyed the wool, but I hand spun it and I hand knitted it. I handed it to him and he was not aware of the fact until I told him that I had made it myself. He said, 'My god, you made this?' He had a very deep voice. I said, 'Yes, sir, I did. It is a legacy from my dear old departed grandma.' He said, 'God bless grandmas'.

Mr CHAIR: That is absolutely fine. You are welcome to stick around, of course, and talk to us on this issue as well, but, equally, it is …

RESIDENT 3: (inaudible) is totally against everything that I want and pray in life is—I am trying to squeeze another minute, every minute of every day, to do what I do. Thanks all the same; this is not coming down my street, sorry.

Mr CHAIR: Thank you for your contribution, though.

VERN: I am all for it.

Unidentified speaker: I am also.

Mr CHAIR: Do any of you have reservations about (inaudible) or the model that we are talking about—any red flags for you (inaudible) other people?

VERN: The only reservation I have got is if you are on your own, with no family around or whatever, you are in pain and dying, you cannot do anything unless you are fully focused.

Mr CHAIR: That is right.

VERN: Do you think if it would ever come in that maybe a power of attorney could take your advice if you want to go?

Mr CHAIR: Those scenarios you just described are available in some other parts of the world in some form, that are a bit more permissive on how they allow voluntary assisted dying to take place. In some other parts of the world the conditions are a little bit looser, if you like; for example, even the dementia stuff, people with dementia might be able to access it. But in Australia broadly at the moment there is a fairly consistent position of not allowing the scenarios we are talking about, so not allowing surrogates, powers of attorney—other people, essentially—to make decisions on your behalf even if you have expressed a prior wish, at this stage.

But one thing (inaudible) on that front is that other states and territories have review boards that have been looking at how their law is operating. Some of them are just in the process now of starting to review how is it going, should we change things, should we tweak things? So, we will get a clearer sense of that out of, for example, Queensland and WA in the coming months and years.

We are at the start of this journey in some ways. As I said, about the fastest this would go is if we write a report, the government likes the look of it, they make a Bill, it gets to the parliament, everybody agrees to go ahead with it, then you would still have 18 months before anybody could use this whilst everyone figures out how to actually implement it. So, we are still a little bit off that timeframe right now.

RESIDENT 2: If you were seriously physically handicapped but not terminal and you have had enough of living like that, would you be able to use voluntary assisted dying?

Mr CHAIR: Unless you are (inaudible) or physically handicapped, but able to express competently your wishes …

Unidentified speaker: No, no.

Mr CHAIR: I have not finished saying. That does not preclude you from it, but you still need a terminal illness, you still need a prognosis of death. For example, the same thing with mental illness. Mental illness, in and of itself, does not preclude you from having access to this, but it cannot be a standalone reason. It cannot prohibit you from being able to access it.

The key common denominators are terminal illness, prognosis of death, doctors agreeing with you. That is the minimum standard in the Australian standard.

RESIDENT 2: You are terminally ill but it is going to take you four years to die, you cannot use voluntary assisted dying?

Mr CHAIR: Not in Australia anywhere at the moment, except for potentially the ACT. Every other state and territory at the moment has a restriction that basically says your prognosis is death from whatever your condition might be—whether it is cancer or a kidney issue or neurogenerative condition; whatever it might be—is you have 12 months or six months, basically 12 months. But not the case—I just lost my train of thought; sorry. It is the first time it has happened in several days. Yes, but not for—can you just pick up where we are at.

Ms WILLIAMS: Four years.

Mr CHAIR: Four years; thank you, Caroline.

At the moment, that would not be possible anywhere, except in the ACT. Theoretically in the ACT, let us say you were suffering from a condition that was increasingly degenerative, the quality of life is getting worse and worse and it was a terminal condition, if you could get two separate medical practitioners to agree that you will definitely die of this, there is no fixed timeframe for that. But none of this has been tested in the ACT yet because, as I said, the ACT has passed the law, but nobody has started using it yet. Those test cases might be tested in a place like the ACT first.

RESIDENT 2: Okay; thank you.

Mrs CARLSON: I have probably got a question and I am not sure—this may lean towards the staff here.

In some places we have learned, due to cultural sensitivities, if someone passes away in the home that home then cannot be used for a certain period of time. I have seen the unique set-up you have got here now, going through the aged-care facility and the independent living. If someone chooses to use it, is that going to be an issue with your unique set-up here? Because there are some options on how and where you would use it, so either in the home or in a hospital. They are the things we are still working through. I would like to know, and probably the community would like to know, because of the set-ups like this, could it still be used here if someone wanted to pass …

CATHERINE: People pass away in-house anyway, whether it is assisted or not. We are trying to set up a palliative care room in each of the facilities, which we do not have yet.

Some of our rooms are shared, so in that case, particularly if they are First Nations people sharing, we do make allowances for that. When that person passes away, naturally the other residents in that room want to move out. We do shuffle them around the facility the best we can.

Mrs CARLSON: Are there any other limitations with work? We know, obviously with this as well, that it will increase palliative care needs. Would that put a strain on this particular facility as well? You have got a lot of beds.

CATHERINE: I do not think so. We would work around it the best we could. We would work with it to …

Mrs CARLSON: Because you have still got the hospital and their unique palliative care system, yes.

CATHERINE: We do, yes.

Mr CHAIR: There is the suggestion that …

Unidentified person: Michael, did you want to say anything?

MICHAEL: Not at present.

Mr CHAIR: Did you want to chip in?

MICHAEL: I am good (inaudible). There are other cultural nuances after someone has passed away, but they are the ones to do with ceremony and cleansing.

Mr CHAIR: Broadly speaking, this report indicates that people who are in aged care or in something similar to that set-up should not be prohibited from being able to access this. That is the report's stance; that is not our determination. The idea is—like in some states and territories, doctors, nurses and medical practitioners are not allowed to initiate the VAD discussion and in other places they are allowed to initiate the conversation as part of general medical discussions. The standard in this report is that people should be allowed to initiate the discussions, and they should not be stopped from doing that in a place like this. Does that make sense to everyone? The option should be available and the information should be available for people. We have not heard about people arguing from that (inaudible), I would say.

VERN: I am just wondering what is the procedure in actual …

Mr CHAIR: How does it work, the nuts and bolts?

VERN: Yes.

Mr CHAIR: So, it varies from place to place, but again it is broadly similar. It is essentially about injecting a combination of pharmacological substances which help people ease off, basically—slow down. More details about that are not readily available here, but are freely available elsewhere. You can ask your medical practitioner about that. To be honest (inaudible).

Ms WILLIAMS: (inaudible) self-administration.

[Multiple people speaking.]

Mrs CARLSON: It is a substance.

Mr CHAIR: It is actively taking a substance under some sort of supervision, whether you self-administer or someone administers for you. Again, I (inaudible).

RICHAV: Just regarding initiating those conversations with the clients and the residents that we care for, we may come to a situation where the client would like the process to happen and the family will not be notified, at least if the resident does not want the family to be notified about their decision. How will you protect them on their decision (inaudible)? We are legally bound to notify next of kin in regard to any decisions they have taken and if they wish not to be (inaudible) shared with their family or (inaudible) have that conversation with (inaudible).

Mr CHAIR: I am going to turn this back on you. First of all, can we just grab a name for the record?

RICHAV: Richav.

Mr CHAIR: Richav, what is your role in this place?

RICHAV: Clinical resource nurse at Old Timers.

Mr CHAIR: You are the clinical resource nurse, so you have interaction with people on these issues all the time. Essentially, all the guidance that is provided in this space at the moment is that we need to work through providing people the opportunity to work out how to have these conversations, how we train in this space, what they can and cannot say and do, but there are no specific prescriptive guidance of this is the set standard for what can be said and cannot be said. This document only says that conversations should be allowed to be initiated, but the substance of that and whether you only have the conversation with a named person or whether their family or next of kin or anyone else would be involved, that kind of thing is not prescribed.

Let me turn it back on you and ask you, based on your experience in this space, what would you recommend? What do you think might be a good way around that?

RICHAV: I have seen it happen when I was practising down in Victoria (inaudible). The reason I am asking this question is we had a scenario where the patient’s choice to (inaudible) voluntary assisted dying did not want to notify the family. That is where the confusion was and then (inaudible) the doctors took over from us (inaudible) so that we can get the (inaudible) work with the process. That is why I am asking this question as to where do we stand legally and liability-wise if we are not informing the family.

Mr CHAIR: As you will be aware, Victoria did this before anywhere else in the country. Some of the curly and difficult questions they worked through and other states and territories are benefiting from that wisdom, if you like. We will be in the same situation with that sort of situation. Right now I cannot give you a definitive answer to where the liability positions would lie in answer to your question because I think it will depend on too many variables that we do not know for certain at the moment. But what we can say is that we would assume, or we would certainly be recommending, that patients who chose to withdraw from care or patients who actively chose to engage in VAD did so in consultation with their health practitioners, whoever that might be, and that all of those people were afforded the correct legal protections and privileges associated with that decision-making.

Some of the Victorian stuff, like you say, was not fully, fully, fully thought out when it was rolled out and so little by little some of those situations have become clearer. Did you have much experience in the Victorian set-up with VAD?

RICHAV: One instance.

Mr CHAIR: One instance. Can I ask which year that was in?

RICHAV: 2019.

Mr CHAIR: So, it was still being pretty …

RICHAV: (inaudible).

Mr CHAIR: Yes, the very early stages of it as well. That is what I am saying. In the meantime there are some refinements that have happened in and around the implementation and governance, particularly in Victoria and South Australia.

Sorry I cannot give you a more definitive answer, but, as I said, to some extent we are gathering information and testing what is prescribed here. This provides us with some guardrails, but not every single ‘i’ dotted and ‘t' crossed.

RICHAV: The reason was when we brought it out in Victoria and I was practising there, we were not allowed to initiate those conversations as a nurse. It is a bit different, and not every patient gets on board (inaudible) duty of care. We had circumstances where certain nurses opted out even to be included as part of that process or to work those shifts when those persons were getting VAD.

Mr CHAIR: That is interesting because we do not get the opportunity to speak to a lot of people in that situation. Did people feel comfortable opting out, that you observed (inaudible) …

RICHAV: (inaudible) religious reasons, many reasons they can provide. That is where I guess (inaudible) facilitate the process. If you are in a nursing home setting and if we have five of the nurses not willing to take part in those processes then do we get support from external to come in and help us still to process these?

Mr CHAIR: That is a really good question. If we zoom out a little, we can (inaudible) in the Northern Territory because the whole Northern Territory has about 1,400-odd doctors and we know that doctors will have to be involved with key parts of the process here. We also know, as (inaudible) said, maybe our best guess would be 20-odd people a year might take this up when it is up and running if that is the case. It might difficult—as the lady who was here earlier said—to justify a completely standalone service that is available on demand.

What tends to happen in other states and territories is there is an accreditation and governance regime. The people who want to be part of that system can essentially opt in to be part of that system. That is probably the direction in a small place like the Northern Territory that makes sense to go down as well.

Even then, for example, in Darwin, there are more private healthcare practitioners, GPs and the like, than there are in Alice Springs. Whether it is doctors or nurses, we know that there is a shortage of them and that not everybody will want to take part, but we want to ensure, consistent with this report, that anyone who does not want to take part does not have to and that anybody who does want to take part has the opportunity to take part. Does that make sense?

RICHAV: Yes.

Mr CHAIR: That is where we are at, if you like, as a principle.

MICHAEL: I just thought of something.

Mr CHAIR: Go ahead.

MICHAEL: (inaudible) the idea of someone passing away in the home, but I believe most of the Aboriginal clients would prefer to pass away on country. They return to country and how that might be facilitated—(inaudible) a return to country service, but I can see how this would impact on that and the resources needed to make that happen.

Mr CHAIR: Can you flesh that out a bit for us?

I will, first of all, confess up to the fact that we have heard lots of people out bush tell us that they would like to have help and choice to finish up. For a lot of Indigenous people that means they would like to be able to get back home with enough time to be surrounded by family and then to figure out, to sort out, their affairs that way. They do not necessarily want medication to end their lives; they are after the opportunity to end their life at a place of their choosing, surrounded by people of their choosing.

We would very much like to work with the definition of 'voluntary' being choice and 'assisted' being to help people to have a good passing, a good death. That stuff we are definitely going to talk about in our report. Can you tell us about your return to country service, how it works and how it might be impacted?

MICHAEL: A client might want to have 32(?) days of leave, able to leave the facility for (inaudible). Some of those reasons can be just in (inaudible) and they might use those to go back for sorry business, but in this case they might want to go back to pass away, around family, on country, somewhere familiar and comfortable. A lot of people (inaudible) on country in the first place to a facility, and the community does not want to let them go as well because in many cases they do not get home. Having a return to country service and that ability to take them back helps them (inaudible). What we provide in order to make that happen, make sure there is a wraparound care service so that everything they are getting here is provided by family or a service in the community (inaudible) just to make it happen.

Mr CHAIR: There will be inevitable challenges, as I am sure you will appreciate, with being able to provide everything that you can provide in this facility, let alone in the cultural care facility, out in a remote community.

As I alluded to earlier, we know from every other state and territory when VAD laws have been introduced in the place, the demand for palliative care services also seems to go up as well. We are trying to assess the amount of palliative care that is available now. In the situation you described and the situation we are thinking through as well, if, for example, somebody is in the end stages of their life and they decide they want to go back to country and we can facilitate even the physical return to country, can we also help people with things like pain relief or patient care assistance out on country?

I cannot imagine that is going to be possible without working with organisations like ARRCS in the Northern Territory. Just coming back to palliative care, and we are talking about here, at the moment you do not have facilities for it. At the moment, how do you manage pain relief generally for the people staying here?

CATHERINE: We still palliate for them, we just do not have a designated …

Mr CHAIR: Room, that is the case.

CATHERINE: Yes. We also have got a palliative care unit up near the hospital (inaudible) as well (inaudible). I mean, it is still possible to do. I guess I wanted to ask the question, from what Michael was saying, if they were taken to country—for us to get one of our residents back to their community where they want to pass away, and they have (inaudible) for voluntary assisted dying—what would that look like on the ground in terms of would they need to be nurse assisted or GP assisted back to the community if there is no healthcare out there?

Mr CHAIR: The short answer is that nobody has talked this stuff in that level of detail.

CATHERINE: Obviously there are going to be restricted drugs, so …

Mr CHAIR: Yes, that is right …

CATHERINE: (inaudible) take those drugs (inaudible).

Mr CHAIR: With that specific pharmacological substance, with the drug itself, that part is a little bit more thought through. It is thought through in the sense that we cannot be having lethal drugs out in the communities; we cannot have things stored onsite. These would still be centrally stored securely in repositories—basically, hospital pharmacies, and then as and when they are required we would have to have people who are authorised to take those things to a place in essentially a FIFO-like set-up. That is what would happen.

As to who those practitioners are and what level of health practitioner they are, that is still also up for discussion, whether it could be a nurse practitioner, or a nurse practitioner accompanied by a GP—whatever it might be.

Again, I am turning it back on you as the sort of expert in this space all the time, what is a model that looks like it would be sensible to you in that space?

CATHERINE: In terms of returning to country?

Mr CHAIR: Yes, return to country (inaudible).

CATHERINE: I could see perhaps if it was a First Nations person going back to their country, we do have GPs allocated to our First Nations. Congress provides our First Nations (inaudible) here, so I guess coordinating something with them where they could assist return to country and follow that procedure through.

Mr CHAIR: So in that situation—again, we are trading in very much hypotheticals here, so we are just spitballing with you to get a sense of what would happen. It might be the case that someone who was here and saw an initial physician who identified, yes, this person is a candidate for voluntary assisted dying. Then after, a secondary assessment done by a Congress practitioner, for example. Then it might be that Congress has decided that they do not want to be involved in the administration part of VAD, so it might be a third party that comes from outside with a healthcare team to help with the actual implementation, if you like, of the voluntary assisted death, partly to ensure that things are done culturally appropriately, that there is no suspicion, hostility, payback—all of those kind of things that we are concerned about as well—so there is a level of separation and we do not blur the lines between people who are there to provide healthcare or palliative care and potentially voluntary assisted deaths.

That is the rough thinking about it. As you would be aware, we only have so many doctors and nurses, and lots of other challenges in healthcare as well as in aged care. We want to make sure that we are recommending something that has a realistic chance of being helpful and not just aspirational and unrealisable.

CATHERINE: Can I ask another question?

Mr CHAIR: Of course.

CATHERINE: The palliative care teams throughout the Northern Territory, are they going to be a part of the voluntary assisted dying?

Mr CHAIR: They could be. We, in fact, spoke today to the Alice Springs palliative care team, the doctors and nurses and people involved in that set-up. Other palliative care set-ups have also made written submissions to us.

While I am on topic and remember, we still have the opportunity for anyone here now—any Territorian or anyone actually—who wants to make a written submission to the committee can do so until the end of next week. We have also got a hotline that you can call if you want to just share your thoughts and somebody will write those down, and then add to our evidence base as well.

The palliative care team have been involved in these discussions because they know, obviously, that they are very closely tied to this. In some other states and territories in the past, sometimes there has been resistance with palliative care people saying, ‘No, I’m not part of it’, and conflating it with the VAD service work, but that is not uniform and true. There are some palliative care people who, for whatever reason, are supportive of it and would like to be involved in it as part of their process as well. There is no harm to ask all about this.

What we have a pretty clear idea about in the Northern Territory is, particularly from the Indigenous cohort, a lot of people are suspicious and fearful of going to hospital. They are worried about going into these settings already and causing harm, so the last thing we want to necessarily do is make that even worse by something that can be seen like, ‘If you go to hospital, it is now a sure thing’. We are trying to remove that.

These submissions that everyone is making are basically all public and online. You can all read them if you want. The Alice Springs Hospital submission, for example, suggested that if—if—a VAD law was passed in the future, they would not want VAD to be practised at the hospital site or health sites. They would want it to

be somewhere else. People might be able to choose to pass away at home or people might be able to choose to pass away at a facility like this …

CATHERINE: That was why my question was for this particular facility, because, yes, with the unit set-up.

Mr CHAIR: That is exactly right.

We only have a couple of minutes left, so we want to hear from anybody else on anything else, if you like. We are happy to answer any questions that we can. We are also not going into thin air; we are just going back to Darwin, so you can always contact us directly or through the committee.

Yes, Yanja?

YANJA: I just want to talk about Catherine's comment about how the return to country program quite possibly could be involved in that sort of stuff.

I was part of the 2022 conversations about (inaudible). The conversations where I was—I am not from Alice Springs; I am from Darwin. The conversations that were happening in the southern region were that it was difficult to fathom if we brought that in where (inaudible). There is an element of black magic that comes into it.

We really wanted to touch the conversation, so it was a really taboo conversation. We had separate rooms for men and women to have those conversations about what protocols could potentially look like. I think (inaudible) were happy to do that. I think that obviously (inaudible) in communities where there are consultations. I think it is really important to make sure that they have the opportunity to definitely say that. A lot of our community mob will not say about the black magic stuff, but I think it is a really massive element of we make this law, we take it into community, we can do all this stuff, but then the community does not really understand it and think that it is a black magic thing and that you are killing our people.

My question would be: how would we, I guess, market that to Indigenous people of the Northern Territory, remote Indigenous people?

Mr CHAIR: At the moment, we are not in a position to be able to talk about how we will publicise it, communication strategy or marketing, for want of a better term, any of this. All we can really do is highlight just about everyone says to us that communication is a very, very important part of this. We know that interpreters are thin on the ground; translation services are challenging; conceptually a lot of this is hard; Aboriginal health workers and healthcare practitioners are limited; sometimes liaison officers might not even feel comfortable talking about these issues to communicate the information on VAD. So, there is not a certain answer to your question. The short version of it is, though, that we know communication is going to be an important part of this if things go forward.

The other thing we can say, whether it gives you a small modicum of comfort or not, is that we have been very surprised, and pleasantly so, at how open people have been with us in the handful of places that we have been able to go. People have been very generous in sharing with us that they would like the help and support to finish up well. Mostly, people have indicated to us that even if they were not to choose this selection for themselves that they are not averse to other people in other places making their own choices, if it is not going to affect their community in terms of stability, decision-making and so on and so forth.

I think part of the communication that I suspect will be in our report, but I cannot speak definitively for everyone, is that we would we be saying that we would want to make it clear that this is very much about the first word, voluntary; the first word ,choice; the first word, nobody has to have anything to do with this if they do not want to, whether they are an Indigenous person out on community or a healthcare worker or a medical practitioner, let alone an individual patient.

Mr KERLE: Old people and young people.

Mr CHAIR: Yes, that is right.

The uptake of VAD for young people who are terminally ill is much lower statistically everywhere, so it is generally older people. But, again, even with old people, as Johnny Cash's friend who was in here earlier pointed out to us, it is not for everybody. For the people who want to choose to not have anything to do with it, that choice will remain. I think I can speak for us when I say that we will certainly emphasise the words 'voluntary' and 'assistance'. How broadly those things are construed is what remains to be seen.

Mr KERLE: I am just conscious we have not heard from yourself; time is running out.

Unidentified speaker: Are you talking to me?

Mr KERLE: Yes.

Unidentified speaker: It is something I believe.

Mr CHAIR: You do believe in it. That is good to know.

Mr KERLE: Do you have any comments you would like to add?

Mrs CARLSON: How you formed that belief. Is there anything?

Mr KERLE: Our time is coming to an end soon, and I am just conscious that we have not had much. Is there anything else you would like to add?

Unidentified speaker: I have only got one hearing aid …

Mr CHAIR: We are just wondering if there is anything more you would like to share with us.

Unidentified speaker: No.

Mr CHAIR: I will, on that note, wrap things up, because we do have to press on. Can I just say on behalf of everyone on the committee and the parliamentary staff, we are very grateful for all of you taking time to talk with us today. Everywhere we go, every extra conversation we have, we learn a little bit more. We cannot promise you the world; we can only promise that we will do our best to put a sensible report to the government and to the parliament. Then, hopefully, the agenda moves forward constructively from there, whatever that looks like.

JEANNE: We have also got a friend and neighbour that supports this too, but, unfortunately, she has been in hospital for a few weeks. She wants to put her name down as a support, so maybe she can contact …

Mrs CARLSON: She could just call through.

JEANNE: Could I have one of these and give it to her?

Mr CHAIR: Absolutely, yes. Any of the paperwork that we have provided, plus all the other paperwork, we can provide through the staff, and everything is available online as well. We will be happy to provide extra information and feel free to reach out to us through the committee staff or even directly as MLAs, you can contact …

Mrs CARLSON: There is an email, or if it is easier there is a hotline number directed for that purpose.

Mr CHAIR: Yes, many, many ways to get in touch with us. We encourage everyone who wants to make a contribution to do it by the end of next week.

All right, folks, thank you very much for having us. It has been great to be out here today. We have had a very productive little visit. We hope we can push things forward as well.

Once again, thank you for your all your time and efforts. Cheers.

Committee concluded.