The committee convened at 11.44 am.

INQUIRY INTO VOLUNTARY ASSISTED DYING
Mabunji Aboriginal Resource Indigenous Corporation

Mr CHAIR: Thanks, everyone, for coming down today. We are sorry we are late.

[Multiple people speaking.]

Mr CHAIR: First of all, let me say I respectfully acknowledge the traditional owners of the country we are on and we pay our respects, all of us, to elders past, present and emerging.

Thank you very much for making the time to meet with us today. We really appreciate it. This is Bernadette (inaudible), who will be helping us with our translation as well—very grateful.

[Multiple people speaking.]

Mr CHAIR: I think that is a good idea, because anything we say too fast or too slow, or slow down, we will not go sentence by sentence today, because obviously everybody understands pretty well.

My name is Tanzil. It is a difficult name, so I wore a nametag today so you remember. I am the Chair of the parliamentary committee that we are all part of here. These are my colleagues; I will let them introduce themselves.

Mr YOUNG: I am Dheran Young; I am the Member for Daly, a member of parliament, and I am Labor Party. The area I represent is Daly River, Wadeye, Peppimenarti, Palumpa, Berry Springs, Dundee Beach and Wagait Beach.

K McNAMARA: I am Kat McNamara. I am the Member for Nightcliff—so the city—which covers Nightcliff, Coconut Grove and Rapid Creek. I am a member of the Greens party and part of this committee.

Mrs CARLSON: I am Oly Carlson, the Member for Wanguri, which covers Wanguri, Leanyer and Muirhead, not far from Casuarina shops and the hospital. I am a member of the Country Liberal Party and a member of this committee (inaudible).

Mr KERLE: G’day, my name is Matthew Kerle. I am the Member for Blain, so I am responsible for Moulden, Woodroffe and Bellamack. We have a lot of people from community who come and stay in Moulden and Woodroffe when they are in town visiting for various reasons. I am a member of the Country Liberal Party and a member of this committee. Thank you for having us, and I look forward to hearing what you have to share today.

Mr CHAIR: We also have Caroline, Katie and Georgia in the back there, who are parliamentary staff who are here to help us and who helped to set up today.

Thank you again, everyone, for coming. The reason we have come today is to talk to you about voluntary assisted dying (VAD). This can be an upsetting thing for people to talk about, we know, because we are talking about death and dying. If anybody feels upset or uncomfortable at any time, just let us know and we can stop. We have support services available and can provide other materials and details if you need.

We are recording today, as we have said, and we would like to record and publish this meeting on the record, so it can be shared as part of (inaudible).

Unidentified speaker: Sorry, Mr Chair, do you mind if we just have introductions as well?

Mr CHAIR: Yes, I was just getting to that.

If you want anything that you say today to be private, just tell us and then we will know that part should be private and you do not want it to be part of the record.

Let us meet who everyone else is in the room, so we get to everybody. Over to you guys.

Ms BAKER: I am Nikita Baker. I am Robert’s EA, our CEO.

Ms SIMON: Shirley Simon.

Ms BAKER: She's a director for—what? Mumathumburu.

Ms SIMON: Yes, homeland.

Ms ANDERSON: Christine Anderson, manager of aged care.

DEANNA: Deanna (inaudible), staff at the aged care.

Mr HUME: I am Brian Hume, one of the directors of this resource centre.

Mr CHAIR: Brian, Nikita, Christine, Shirley, Nikita, Deanna.

Mr HUME: I would also like to say welcome to Borroloola; welcome to the country on behalf of the clan members of the four clans, here in Borroloola, the Yanyuwa, Garrwa, Marra and Gudanji. Welcome.

Mr CHAIR: Thank you very much for saying that.

Before we hand over to you and find out what you all want to share with us, we will just explain it a bit to know that everybody is on the same page while we are here. As Dheran, Kat, Oly, Matt and I all pointed out, we are all members of parliament. We are five of the 25 members of the parliament. We are from parties, but we are all in the same committee, the Legal and Constitutional Affairs Committee. Our committee was tasked to look into this report.

One year ago, this report was made, not by us or the parliament, but by independent experts, doctors, lawyers—a lot of different people who were looking into how people can have more choice and help to finish up. That is basically what this is. The government wants us, as a committee, to look at this and see if the ideas in this are good ideas or if we can make them better, and what everybody accepts is that when they made this report and talked about voluntary assisted dying (VAD) before, maybe they did not talk enough to people in communities.

Our focus is a lot on going out to communities. Yesterday we were out at Ngukurr, today we are here, next week we are in Numbulwar and so on and so forth. Over the month of August we will try to get to as many places as we can. We produce this report and then write our own short documents, which I will leave for you. There is a one-pager here that we will pass around to everyone. Do we have more copies of this?

[Multiple people speaking.]

Mr CHAIR: We know not everybody wants to talk about finishing up. (inaudible) whilst we use this idea if it becomes a law, but we still want to know what you think. That is the important thing because it is a law for all of the Northern Territory, and we know 30% of the population of the Northern Territory is Indigenous people, so it is important that we know what remote community people think about this as well.

That one page that we just handed out is basically—we invited everyone across the Northern Territory to write to us, send us a submission and tell us what they think about this report, particularly this one. This is a big report. We wrote a short one which is a consultation paper, which we will leave for you as well. You cannot read it all now, but …

[Multiple people speaking.]

Mr CHAIR: Basically, we made that report and asked 250 organisations across the Northern Territory to write to us, tell us what you think. There is also a hotline where people are calling and telling us what they think. We wrote that 50 pages, and recently we did a report as well to tell everybody so far what we have done and what we will do next. All these papers, we will leave with you.

We also go on the radio and television, that sort of thing, to let people know. These are the press releases that we put out as part of it as well. We will leave all of these and we can come back to them later, and you can look at them in your own time. Today we really just want to talk and explain anything you want explained, and we want to hear what you think about this report.

The first thing, maybe to the Chair, I might pass over to you guys to tell—first of all, does anybody know about this report from last year on finishing up? No? So it is new to everyone, basically.

Unidentified speaker: Yes.

Mr CHAIR: Okay. So if we go back just one more step, 30 years ago you may remember there was a law passed in the Northern Territory, in 1995, when Marshall Perron was the Chief Minister, a long time ago. That was the first law in all of Australia for people to have more choice and help to finish up if they are very sick, if they are terminally ill. Then one year after that law was passed, the federal government cancelled that law. They said that we could not do it.

Twenty-five years later, in 2022, the federal government changed its mind and said, ‘You can have that law again if you want’. In every state and territory there is a VAD law. Only the Northern Territory does not have one.

Ms ANDERSON: Is this the same as euthanasia?

Mr CHAIR: Yes, that is right. Back in the day, everyone used to call it euthanasia. Now, everybody calls it voluntary assisted dying. Those are not our words or our choices, and we know a lot of people—‘voluntary’ would be better if we just said ‘choice’. ‘Assisted’ could mean all sorts of things—but help.

What this report proposed is 22 different recommendations. It suggests that if somebody is terminally ill, so they are definitely dying, they can go to a GP or a doctor—any doctor—and ask, ‘Am I sick enough to try to get VAD help?’ And if that doctor agrees, a second doctor—who is usually a specialist in that illness—has to also agree. If both those people agree and there is some time in between, it goes to a final person. What would happen is that doctors and nurses would help someone finish up where they want to finish up when they want to finish up, rather than them having to suffer if they are in a lot of pain.

Ms ANDERSON: We get a lot of people come home to country, so would someone come here and do it if someone wanted that?

Mr CHAIR: Possibly, yes, that is exactly it. Maybe it would be helpful if you started by telling us about what you guys do here and a bit about the palliative care set-up here.

Mr YOUNG: At the moment there has been no law set up in the Northern Territory for this to happen, so a lot of the answers we might not have. We are talking to people, and when all of us here will write another report, and it will go to the government, and the government will decide if it wants to make it law.

Mrs CARLSON: That is why it is important we come out to community to get your views, because the last report did not really consult with enough remote communities. We know there are varying ideas on how you want to finish up. Some people cannot suffer too long; they cannot handle the pain and the suffering, so they want this type of law so it gives them some dignity and stops the suffering.

We know in some cultures and religions it is probably not acceptable, finishing up this way, but this is really important why we are coming to you guys, because your definition and interpretation of dealing with death is very different from a lot of people. It is important for us to have your views because in our report we can put some of that messaging in there on how different people finish up, and there could be other pathways that when we consider the law, it is looked at on all the different pathways that are possible.

Ms ANDERSON: If I wanted to do that, then my family, they will all come in and say, ‘No, that’s not what happens there’.

Mr KERLE: That is important and we would like to understand, because that is probably (inaudible). I have a Western background, and my background is very individualistic, so I do not have experience with that kind of decision-making, so it is really important to share how that decision-making works, so we can put it in the report, and that can be a recommendation back to government.

Mr CHAIR: Dheran is right; we do not have all the answers, but what we have is this model. We got asked by the law minister, the Attorney-General, to look at this report and the suggestions. Their suggestions do not say a lot at the moment about finishing up on country. They do not say a lot about palliative care. They know that we need extra palliative care help, but it does not say much more than that.

It is helpful if we understand a bit more about how your set-up works here and how you help people at the moment when they are finishing up, and decision-making structures, because we were just saying, for example, family. In this report it is just about the sick person who has the choice. They do not think about families or clan groups or anything like that. We would like to include that kind of information if you would like to share it with us.

Ms ANDERSON: It is the same going for when they fill out the APPs and they say they want to get buried on country, and in the end, families end up fighting where they want that person buried instead of listening to their choice and what they wanted. That happens a lot now, doesn't it?

Ms BAKER: In Aboriginal culture you have the *junggayi* of that person that is deceased, and you have to take all of that into consideration. When the person has passed and there is that many bosses of them.

Ms ANDERSON: (inaudible) body.

Mr HUME: Being Indigenous is very—this is a very complicated (inaudible). I have heard over the years, growing up, this is the way we were taught. I found that (inaudible) the individual was – they felt more sick away from home. Whereas, they would much prefer to be back home to pass away. Like (inaudible) I suppose in every culture. I not only grew up in Borroloola, I have been working up through Arnhem right over to Daly. Indigenous rules are very complex, very complicated, and each (inaudible – furniture moving) the way they set out their rules. (Inaudible) in many communities it is much preferable to be brought back home to family and pass away with family.

Mr CHAIR: At the moment, is it easy enough or hard, are there issues with people coming back to country to finish up?

Mr HUME: I think they appreciate—whoever the person is, they appreciate going back to country (inaudible). They are born and grow up, and once you are back here, it is up to the individual *junggayi* (bosses) to sort out, to stop complications and put that person in that specific area.

Mrs CARLSON: Brian, I have a question off some of the comments you just made. It is probably a bit clearer already that the preference is to return to country and be around family and supported through that, so my question—which then ties in—is what this is trying to achieve is people finishing earlier, so not going through that suffering. Possibly, some of these families do not have support like you guys, so that is why they want this law.

Mr HUME: This is very complicated (inaudible).

Mrs CARLSON: So in your culture, and if we are trying to find maybe something that would tie in with your culture and still with this, my question is more about how you guys determine suffering and how long these people are at home. How does the family support the sick person in that last stage? Are they comfortable? Is the pain …

Mr HUME: There is that difficult (inaudible). It is up to the individual. It is their choice, but it also collides with cultural side of things. That is what makes it very hard.

Mrs CARLSON: There is I know a lot of people who do not like to take medication because they just do not want to do it, and they would rather suffer through the headache and do not want to take a Panadol, but death is also something that can be quite sensitive for the person and family. I am interested to know more about the effects on the person and the family in that last stage. Would they need earlier intervention and help in finishing up or are you accepting that, in your culture, you finish up when the time actually is and go through all of that? Does it override that it is important by finishing up, even though you are going through all that pain period and the sorrow beforehand with that person, but that is your way of interpreting going in peace as well (inaudible).

BERNADETTE: What I'm saying, like, [Kriol spoken] 'Oh, you pain (inaudible) medicine. You just go away peacefully. But, as my culture (inaudible) family is (inaudible).

Mr HUME: That's where the complication is.

Mrs CARLSON: Would you rank it as more important and higher importance than (inaudible)?

BERNADETTE: The difference with Aboriginal culture and white man is they say, 'Oh, you're in pain. We might give you something. Do you want to go in peace?' It is personal, if that person is really strong enough to say, 'Yes'. But with our culture it is a bit hard. We do not want them to suffer but just watch them die peacefully. That is part of our culture.

Ms ANDERSON: At the aged-care centre we have people who come back from Darwin. The doctors will ring us, they come into aged care and this is their end of life. We look after them. The family more or less moves in; we give them a room and they have one carer. We feed the carer and the person, and other family members can come to the room and stay as well. Sometimes I tell them, ‘You can pitch your tent up outside if you like, when it gets closer to the time’.

When they start getting in a lot of pain, that is when the clinic comes in and starts putting the syringe drivers and things in. Sometimes you hear them, like, some of them will say, ‘Why can’t I die now?’ You hear it come out a lot—instead of going through this suffering. You can hear it.

Mr KERLE: That is why we are here. That is what this thing is about. It is not about trying to make anyone do anything. It is only like, when someone is at that final point and they are in a lot of pain and they are ready to go, they can have that choice so that they do not have to go through all the pain before they finish up. When the pain is too much, they can say, ‘All right, we shut now’.

Can I ask a question, because it is important for us to understand. We talked about *junggayi* before. What is the best way to translate that into English? Is it like bosses?

Multiple speakers: Boss.

Mr KERLE: Like the cultural authority over that person?

Multiple speakers: Yes.

Mr HUME: (inaudible) the caretaker of the country as well.

Mr KERLE: Is it one person, or it might be a few different people with different aspects?

Mr HUME: (inaudible) my cousin is the boss (inaudible).

K McNAMARA: Just moving on, just broadly, are you able to talk about how decisions get made in your community? Just to let us understand generally, when families are making decisions about all kinds of things, like with *junggayi*, how do you make decisions around people’s lives?

Mr HUME: It is mostly the elders.

K McNAMARA: Mostly elders, yes.

Mr HUME: The old council, the old men who are the ones that make the choices. If anybody needs to be banished from this place (inaudible), it is up to the elders. The old men were sort of like guardians and, in certain aspects, chiefs. They are different clans. They are the ones who deal in country. Like I said, Indigenous law is very complicated. Different (inaudible) and different rules you have to follow.

Mr KERLE: In this scenario, if someone was finishing up and they are out here, and the family was around and they were in a lot of pain, would the *junggayi* have to make the decision for them to be able to take some medicine to finish up sooner?

Mr HUME: That is a very sensitive one. I don’t think the *junggayi* can go as far as that because there may be retaliation. Nowadays, everybody is educated, but that could be also misinterpreted as it’s a very complicated (inaudible) decision that (inaudible).

Mr YOUNG: Picking up on Matt’s point, and just to clarify, you have to be sick and dying. For example, if you have cancer and you are going through chemo and the doctor says, ‘Look, we can’t give you any more chemo. Unfortunately, you’re not going to make it.’ In this report it is saying that, first, you cannot get better; second, you have to see a doctor—two doctors. You have to have consultation with your doctor to consider taking the voluntary assisted dying medicine, and then you have to see another doctor. So it is not just because you are in pain; you have to be sick and the doctors say, ‘Sorry, we can’t help any further’. Then if it becomes more, that is where we work, but then there are also the cultural complexities with all groups in the Northern Territory. It is different everywhere we go across the Northern Territory is so ...

Mr HUME: No one community is the same. There are difficult dialects; different ways of doing things. This is a very sensitive issue, so it is different for each individual. I guess it is up to the individual—and the family if they are agreeable. It is really hard (inaudible) very complicated.

Mr CHAIR: There are people who are worried that if a law like this gets made—to make sure it is good for everybody in the Territory, not just good for people who live in Darwin. We are trying to think about when we write our report, what, if anything, can we do to make it also good for people out bush? We know that there are probably Aboriginal people who will be less likely to want to use VAD laws; we know it is less likely, but we still want to make sure that if they wanted to use, if family agreed, then they could still do it.

One of the big issues you were bringing up before, Christine, was people coming out here to finish up. That already happens a bit. Does it happen enough? Do you have any hassles in making it happen?

Mr KERLE: Transportation, people getting here in time.

Ms ANDERSON: Yes, they normally fly them back on the doctor plane, and we just take over from there. The clinic comes in, does all the medical teams. We support the family, and family just come in and we just do the rest, don't we?

Mr YOUNG: That person will usually come stay at the aged-care centre or back with family?

Ms ANDERSON: Yes, stay at the aged-care centre—because there are too many people in one house, overcrowding in the houses, so they will come up to aged care. If the person does want to stay home, we will give a bed and probably other equipment they need, and then provide meals, and then they will look after that person in their home.

Mr YOUNG: So sometimes they will go home …

Multiple speakers: Yes.

Mr YOUNG: … and be cared for by family.

Mr HUME: Some of the others prefer to go back into the community (inaudible), because it makes them happy.

Ms ANDERSON: We have had a couple who have come home, but they have passed away just before they landed and things like that.

Mr YOUNG: What about people coming back from town, from Darwin to Borroloola then going out on country, on their homelands, is that also (inaudible)?

Ms ANDERSON: Here in Borroloola, because if they are out on homelands it is too far away for the clinic.

Mr CHAIR: So Mabunji and Malandari, this is a really good aged-care set-up. Not everywhere has the same kind of set-up you guys have. We know some places do not have the services you just described. Again, we are trying to figure out how we might help people come back on country, if that is part of the assistance. As you said, a couple of people passed away before they made it back.

Ms ANDERSON: Yes.

Mr CHAIR: Does that happen often, or has it happened very often at times?

Ms ANDERSON: In the last three years, probably twice.

Mr CHAIR: I guess they were obviously very sick before they got on that plane.

Ms ANDERSON: We were having renovations at aged care, so we could not bring anyone into the centre. A lot of people were just finishing in town then, passing away in town, and family would go up there.

Mr KERLE: I am just touching on something you said before, Brian. I want to get it so we understand, because you mentioned about payback, if *junggayi* were making decisions about that sensitive topic. Are there ever situations where someone dies, say, naturally—they finish up naturally, but then some people might think that it was someone's fault and there is payback. Is payback a big issue if you admit someone's death was not fully natural? Is that something to do with …

Mr HUME: I am going back here, because, like I said, people (inaudible) very educated, but there is always that blame that needs to go on somebody. If you do not follow Indigenous protocol and you may step out of line, you could be in trouble (inaudible) making decisions instead of (inaudible) whole mob, sort of thing, you could be the one to blame. (Inaudible) we don't use spears (inaudible) fisticuffs.

Mrs CARLSON: Christine, I have a, might be a (inaudible) question, but back to your point about the persons who passed away before they landed back on country, would it make a difference if they were able to make a decision earlier, as in try to start the process—with VAD …

Ms ANDERSON: With my point of view, I say yes.

Mrs CARLSON: With VAD we have a conversation, and we start having that conversation earlier.

Ms ANDERSON: Like in town.

Mrs CARLSON: As part of the process of being told …

Ms ANDERSON: Have their choice, yes.

Mrs CARLSON: Would it be a sensitive matter to bring it up earlier so we can try—or is it …

Ms ANDERSON: It was really taboo before, but I think it is becoming more acceptable now. Do you think, Brian?

Mrs CARLSON: Do you think it is acceptable now?

[No audible answer.]

Ms ANDERSON: Yes, some people, if I asked them a question about dying towards the end of life, and they will say, 'Why talk like that to me? You're giving me bad luck.' So you have to be really careful what you say, so we just look after them and the family come in and look after them.

Mr KERLE: That is a good point, because that is one of the things we have to consider, whether the doctors and nurses—healthcare practitioners—can suggest it to the patient or whether the patient has to ask for it.

BERNADETTE: And I think have an interpreter in there, because a lot of people might not understand.

Mrs CARLSON: So what would it be more culturally appropriate considering we need to …

BERNADETTE: With my pod(?) and my mob in the community from Maningrida, when they hear from the doctor saying, 'This person's terminally ill and coming back', (inaudible) they bring the family people up and say, 'Okay, we just accept that. Just keep an eye on him'—pass away slowly. That is their belief in my community. I do not know about any other community, but that is how we …

Ms ANDERSON: Shirley said if she was really sick in hospital, she would not like that mentioned to her.

Mrs CARLSON: Yes, that is what we need to consider.

Mr KERLE: That is what we need to know.

Mr HUME: I guess it is up to the individual. Depends how they feel about (inaudible).

Mr KERLE: Brian, we know that when they did this report and when they did earlier work as well, there were a lot of people in town, in particular, majority of people, maybe like 75% some people suggest, who would like some choice if they are suffering and they are towards the end. Let us just say, hypothetically, if our law does get made like this, even if this community or the people in it are not interested in using it, how would you guys feel about that law existing and other people having a choice? Is that a problem for you?

Mr HUME: It comes back to that same question, it is up to the individual, I guess. If they don't want to make family sad, and other family members agree with that individual, I guess it is that individual's choice.

Multiple speakers: Yes.

Mr HUME: I reckon (inaudible) he would not agree—most people would not agree. Culturally, they prefer to pass away naturally.

Ms ANDERSON: When someone is dying, there is a lot of family in the room with them too, all the time. Then at the end, like Brian said, you talk about the *junggayi*, and then we leave, and it is up to them what they do—smoking and all that. And he is in charge of that, in charge of everything and all their things in the room. At aged care I have to be there in case they might grab our TV or something like that. That belongs to aged care, but anything that belongs to the person, they are the boss.

Mr CHAIR: Before you leave the room, as we enter that stage, in the aged-care facility here, do you have people who help with pain relief when somebody is …

Ms ANDERSON: That is the clinic.

Mr CHAIR: That is the clinic that does that.

Ms ANDERSON: The clinic does.

Mr CHAIR: So by the time they come to you there is no more pain relief; is that right?

Mr KERLE: The clinics manage it.

Ms ANDERSON: The clinic manages all the pain.

Mr CHAIR: Right; sorry.

Mr KERLE: Is there a nurse there with the person—when they manage the pain, is there a nurse there administering? How does that work?

Ms ANDERSON: Yes, the nurse comes up and administers it.

K McNAMARA: I think it might be also helpful to talk over details—like we said, this is not a law that is here yet, but the ideas in this report—because we do not want people to misunderstand or think that it is just going to happen everywhere, so it is good to point out that the ideas in this report say that if this law is to happen, the Territory probably should have it as a separate thing. You have healthcare and hospital, and you still go there to get better. Then you have palliative care, and then VAD would be separate so that people are not worried that if you go to hospital—it does not happen.

Unidentified speaker: So they do not confuse.

Multiple speakers: Yes.

K McNAMARA: Yes, so it is important to know that, and it will probably only happen in one place. Probably in Darwin—probably—there might be all the nurses and doctors who work there, and then if someone wants to use VAD in a different area of the Territory they might travel to go see them there, or they come in, so it is very important that people understand it is separate to the hospital and that it is only ever if somebody asks for it. Also, they have to be of sound mind; they have to be able to make that decision. There are lots of checks to make sure it is okay.

Because this happens in every state in Australia, we can also see how it happens. A lot of people who are dying and scared will ask for it and go to the doctor, but then they might not use it. They just want it there for comfort, like, ‘If something gets really bad, I can use euthanasia’, but then they might pass away naturally.

Ms ANDERSON: We deal with the palliative area in Darwin as well. If we have things to ask or—some of them are there and then they come to us.

Mr KERLE: Is that like Alan Walker?

Mrs CARLSON: No, palliative care.

Ms ANDERSON: There is a palliative section down the bottom. It is really good in there, with good nurses.

Mr CHAIR: In most places we know when they introduce a law like this—in other states—the need for palliative care also goes up. We are trying to work out if there is enough palliative care help in other places as well. Can you tell us anything about that for here?

Ms ANDERSON: What have we had? Two this year, two here that we looked after, and they have both passed on now. We had another one here, but she has gone home.

Mr HUME: The main thing is how you interpret things, because people misinterpret sometimes. They need a full understanding of how the situation has to go, you know? If they do not have a proper understanding of this—a full understanding. You know, some people, might decide.

Ms ANDERSON: We have paperwork to do and go out to the clients, and right at the bottom of the page it has that bit.

Mrs CARLSON: Do they understand?

Ms ANDERSON: Yes, no-one would answer those questions before, but now people are starting to say what they want, so this would be a good thing to put in their care plans and things as well, you know, while they are still here.

Mr KERLE: That is an important thing. This—even the report, everything we are looking at …

Ms ANDERSON: Not just waiting for the last stage but earlier, when they first come into care. Things to ask.

Mr KERLE: If it became law, you have to be all there up top; once people cannot make a decision, then they cannot access it. It is only for people who choose and they know what is going on, and they are still there. Once they are not there anymore, they cannot access it.

Mr CHAIR: For example, dementia. This is not applicable for anyone who has dementia, and that is the case across the country as well.

Ms ANDERSON: Like our intake forms when people first come in.

Mr CHAIR: Understanding what the forms …

Ms ANDERSON: Yes, and when we go through everything, maybe that is a thing at the end we can start putting in.

Mrs CARLSON: Obviously, the advance personal plan is currently a legal document, and you must sign that before you acknowledge any unsound mind. Do you think then, in that advance personal plan, because someone with dementia, Alzheimer’s and any memory issues, cannot use VAD. But do you think then it would be of benefit that they would stipulate that in their advance personal plan that it is an option for later? They sign when they are of sound mind.

Ms ANDERSON: Yes.

Mr CHAIR: On the APPs, which you know very well, there are things like ‘do no resuscitate’, the DNRs, when people tick a box if they want, so there is a suggestion in that regard that if this ever became a law—if it became a law—then there could also be the same sort of thing, basically saying, ‘If I’m ever in that situation, I would be a willing candidate for that’. Do you think that kind of information would be useful in that documentation?

Ms ANDERSON: Yes. I think now, going back and thinking about this in our paperwork as well—to put it in our things. We do have APPs and the clinic has theirs. Right on the bottom, that would be good.

Mr CHAIR: Do you have questions about the model? Remember like Brian was saying the details here, do you want us to explain any of what is in here at all, like what they were suggesting? We have sort of talked around a lot. Dheran said it, Kat said it, we have all said a little bit, but, basically, to be eligible in this suggestion at the moment, you have to be over 18 years old; you have to be terminally ill, dying—a first doctor has to say you are definitely dying within 12 months or less—and if you pass that, there is a waiting period before you have to then see a second doctor.

That second doctor has to—in some places, some states, they have to be a specialist in your condition, so if you are dying of cancer they have to be a cancer doctor; in other places it can be a general doctor that agrees with that second opinion as well. If there is agreement about that, then the third stage, the administrative stage—in other places—involves doctors and nurses, and they usually find a location where they are doing the finishing up, and someone will come with the medication and help them finish up when they want, where they want. That is basically it. This is very specific.

Mr YOUNG: At any stage during that process, you might go see a doctor, then you go see a second doctor, but you can still decide, 'Actually, no, I don't want it' at any stage. Just because you say yes does not mean you have to take it. There is always that choice for what you want to do throughout the whole process.

Mr CHAIR: At the very last stage, if somebody has passed all of those things and they are suffering and sick, they made a decision, and it is all legally sound, then a doctor and nurse will come to that person and help them finish up using an injection. It is an injection. Up until that very last stage—Dheran is right—you can always say, I have changed my mind.

What we know, though—think of these words, 'voluntary' and 'assisted' in particular. 'Voluntary'—choice. We are starting to realise we need to talk more about giving people choice. It is your choice; you do not have to do it. With 'assistance', that is the word we are more interested in because this is about assisting people just at that last stage. We are now thinking about whether or not in Indigenous communities we could provide assistance more generally for people to finish up and be given more choice by maybe coming back to country earlier, or whether or not we could introduce these conversations earlier. Those are maybe ways this would be helpful for people out bush, rather than something that is bad for them.

If you can think of things that we could do using this law that might be helpful in this community or in this clinic set-up, that would be really interesting to know for us as well.

Mr KERLE: You do not have to answer now. If, a couple of days down the track, you think of something, you can always just email it through, and we can add it in. If you cannot think of anything …

Ms ANDERSON: Just call us up or chat to Nikita, and Nikita can inform me.

Mr CHAIR: People are writing to us and giving us submissions. People are also calling all the time as well. We have, basically, the rest of this month to collect as much information as possible.

Ms BAKER: We have a board meeting next week too, and we will table this at the meeting to get feedback (inaudible).

Mrs CARLSON: Fantastic, thank you.

Mr CHAIR: That would be really good. I am just mindful—I know we started at 11 am, but I am unsure how we are going for time.

Unidentified speaker: I have no idea what the time is, but we can—do you want to grab some lunch and then we can sit down and keep talking, if you like; does that work?

Mr CHAIR: Sure, that is fine by me. Let us do that. Let us grab something to eat and then sit back down and chat.

Committee suspended.

Mr CHAIR: We will get started and let the others come in when they come in. Thank you for a delicious lunch, first of all. I was having a chat with the ladies over the other side, and Christine was telling us some useful things about this community, the RN and EN nursing situation, and also the interactions with palliative care. Do you want to fill everyone in on the conversation we were having?

Ms ANDERSON: We have an RN at aged care, and he does what he has to do, and then we deal with the clinic most of the time. We have palliative care in Darwin as well, and we deal with them a lot when the time comes for people to come home.

Mr CHAIR: The fellow who has been here for three years?

Ms ANDERSON: We have a registered nurse. He came as an agency nurse. We had an EN at aged care for about three years. He came along because the other one was leaving, and he was only supposed to be there for three months, I think we had him, Deanna?—come in for three months and then go. I said to him, 'Can you stay so you can help me with all the paperwork?' He said, 'Christine, I'm just a bubble. I just go everywhere.' Then he fell in love with the place and he stayed on and is still with us. He is an Indian; he works with agencies in Melbourne. He is from Melbourne—Makesh.

Unidentified speaker: I have had a few chats to Makesh.

Ms ANDERSON: Yes. He is a good fella. His English is getting better.

Mrs CARLSON: Are you teaching him the local language, then?

Ms ANDERSON: He can pick it up like that.

Mr HUME: Transition, very good.

Mrs CARLSON: He is investing himself. Good on him.

Mr HUME: A few guys in housing, (inaudible), mechanics. They started talking language to me and I thought it was one of the boys.

Ms ANDERSON: Yes, so he is with us. I think he will be—it is up for proposal to change; I want to change my position. I have been there for 24 years. I might move out slowly and just lighten the load because it is doing my head in, all the new things coming out. I want it to be an Aboriginal—what do you call it, Nikita? What is its name?

Ms BAKER: The liaison officer.

Ms ANDERSON: Yes, like an Aboriginal liaison officer thing at work. Then I could just work with the nurses. Like, now I am telling him a lot of things and teaching him how to do everything, and he always wants to know how come no-one comes to work, only when I am there. I go pick them up.

Mr HUME: This is one of the land main things in communities—getting these young people motivated. (inaudible) was just talking about a role model. (Inaudible) people away—I thought it was a good idea back then to go and visit other communities and see how they operate and (inaudible).

Ms ANDERSON: You are supposed to go over to one place—it might be Milingimbi. What is your aged-care centre called?

BERNADETTE: I am at Maningrida.

Ms ANDERSON: Maningrida, what is it called there? We are supposed to go over there and have a look, I think.

Unidentified speaker: Is it Mala'la?

Ms ANDERSON: That's it, Mala'la—to see how they run—that will be good.

Mr CHAIR: Christine, the stuff you were telling about your mum and the APP and DNR stuff is really useful.

Ms ANDERSON: What did you say again?

Mr CHAIR: Remember we were talking about the APP and the DNR, and the conversation you had surrounding that, about maybe including these kinds of things on paperwork and giving people choice—the capacity to make a choice.

Ms ANDERSON: Yes, when they first come in you have to fill in all their paperwork, and put that on the bottom as well in there—I think that would be a good thing. Probably later they could change their mind and say no. Before all this started, when my mum filled in her APP and all her paperwork and she gave it to me, when I looked at it I said, 'No, mum, I'm not going to resuscitate you?' And she said no. I had tears in my eyes when I read that. She said she just wants to go like that. At that stage, I thought, after seeing so many people coming and going with us, you know, passing away, you start thinking otherwise.

Mr CHAIR: You have seen a lot of people come and go and pass here, haven't you? I mean, that is what you are saying.

Ms ANDERSON: Hmm.

Mr CHAIR: And lots of different nurses and healthcare practitioners at a time—but you have also seen over time that when people are in pain, it is not unusual for them to be helped so that they are not in pain.

Ms ANDERSON: Like with the clinic with the morphine, they just keep giving you more and more morphine until you do go. That is the thing that a lot of families probably do not know. They just ask how comfortable you are, 'Are you in a lot of pain?' You could say yes, so they get that morphine up and then, probably three or four days, and yes, family is gone.

Mr CHAIR: As we were saying, it is not an uncommon thing, but you do not know about it as much in remote community settings. In the hospital setting, you would have doctors tell you that kind of thing is commonplace, you know?

Ms ANDERSON: Yes.

Mr CHAIR: So it is useful to know that the same sort of standards apply in hospital as well.

Nikita, you had some thoughts too, didn't you? When we were out there. Putting you on the spot.

Ms BAKER: As my personal opinion, for me, I do not know, the last moments with a family member—I think that it is better for the family, but then you have the individual to think about too. For me, I would rather have that last moment with them and they go naturally ...

Ms ANDERSON: Nurse them to the end.

Ms BAKER: That is what I think.

Mr CHAIR: We were both saying that when you are younger it is easier to put it out of your mind. You do not want to think about it, but then the more of this you see, sometimes that changes your mind, particularly if people are in a lot of pain. One of the things we were also discussing outside is that it is really important for people to have enough time back on country, with family, so they do not just turn up when they are so sick that it happens too fast and nobody has time to spend before they even get back.

That is one of the things we might end up talking about in our report about how it is important when we are helping people make the choice, or helping people to move on, that actually coming back to country earlier would be helpful if we can encourage that.

Ms ANDERSON: That would be good. You know how some people want to spend time with the family member, not just a last-minute—because you normally get two or three weeks, two-and-a-half weeks, when they do come home.

Mr CHAIR: We were having a great old chat; hence we are having a chat again. Do you guys want to …

Mrs CARLSON: Coming back to time, is there an appropriate or better—what would timing look like to you guys? Do many families have to come from other parts as well? Is that what you try to incorporate here? From other remote areas as well?

Ms ANDERSON: Yes. Some families might be Darwin, Katherine, Alice, and then the money situation for them to come. That is a hard thing as well. People come from all different areas in the Territory.

Mr CHAIR: If a law about this was passed, it would end up costing money to set up, so they made sure people would access it in a fair way. The conversation could be had at the time as well about what we are doing to help people out bush finish up, so it is useful to have these conversations with you so we can—we are not guessing.

Ms ANDERSON: Most of them just want to come home to country and be looked after by family, and just to pass away here with family all around them. That is what most of them want; they put on there—have their family around when they do go. Even if they did go the other way, just let all the family know, and they could come in.

Mr CHAIR: The heart of these laws in other places is to be compassionate, to do the right thing. It is not to punish anybody. The idea of these things is to help people have a good death, a good way of being able to pass on, rather than suddenly or uncomfortably. What does a good death look like here, do you think? If you can summarise for us, what is a good way for someone to pass on here?

Mr HUME: Just coming back home to family, with all your loved ones around you, speaking to you, letting you know that they are there. And just pass away with loved ones all around you.

Ms ANDERSON: And even you get the older ladies, they will go in and sing, clap. (Inaudible) sing before? Yes, and it is really nice, listening to that. And they just lie there. Shirley and them used to come up and sing to certain individuals. It is just good, that person just lays there, because they can hear and everything and just listen.

Mr CHAIR: You brought it up earlier, Christine, when you said the word ‘euthanasia’. Euthanasia used to be a word for this before it became voluntary assisted dying. Euthanasia is a Greek word—Greek or Latin, I forget—but it means ‘good death’. That is what it actually means. So what we are trying to do here is help give people choice and help to finish up—a good death. For some people, a good death might be that they choose by themselves to have an injection somewhere. For other people it might be that they need more time to come back to their place, not to have an injection but to have more time in their country and with family. That is what we are hearing a bit of now.

Mrs CARLSON: I think sometimes—in that report it mentions ‘consider people with cultural aspects’. However, it has not really been determined until now that we are listening to you about what that really means. I think we can now expand it, I suppose, in this document.

Mr CHAIR: Absolutely. All right, folks, we have to get to the next place, and I keep getting told off when we go over time, so I do not want to make us be late again. Just before anything else, can I just say, honestly and sincerely on behalf of all of the committee, thank you so much for sharing with us. Thank you for your hospitality and generosity. Thank you for the delicious pies, which I ate most of.

It is really good for us to have a chance to come and talk to you all like this properly, so thank you. I hope we have more conversations like this. This will not be the last conversation, hopefully.

Mr HUME: I think the most important thing is that people have proper understanding of it. And then, perhaps, once they have an understanding you will have many more coming out saying (inaudible).

Mr CHAIR: I think you are right; communication and understanding. We will take that on board.

Mr HUME: Everywhere communications happens every day. Where the meetings I used to go to (inaudible – furniture being moved). The most important thing is communication (inaudible) understanding (inaudible). That is why this boardroom is still here, 45 years later, because we understand each other, and we make the right decisions (inaudible). Once you have clearer understanding of the situation and what you are doing (inaudible). Thank you for coming.

Thank you for coming to country.

Mr CHAIR: We will certainly try.

Committee suspended.

Borroloola Local Authority

Mr CHAIR: First of all, thank you very much for making time for us today to be able to come down. Let me start by respectfully acknowledging the traditional owners of the country and paying respect to elders past, present and future. I am here today with my colleagues. My name is Tanzil Rahman. I am the Member for Fong Lim, one of the Darwin seats, and I am the Chair of the Legal and Constitutional Affairs Committee.

I am here with my colleagues: Oly Carlson, the Member for Wanguri; Dheran Young, the Member for Daly; Matt Kerle, the Member for Blain; we may be joined at some point by Kat McNamara, the Member for Nightcliff, as she just quickly had to pop to the doctor at the clinic; and also from parliamentary staff we have Caroline, Georgia and Katie, who are helping us to record and take minutes of our proceedings.

We are also accompanied today by Bernadette (inaudible). She has been helping by translating for us all day today. I am guessing we will have less need for her services in this room than we did at Mabunji earlier, but certainly we will use her as required. I really thank you for making space in your busy agenda. Obviously, you have other things to do today, so we will get straight into it.

We are here today to talk about voluntary assisted dying (VAD) which I think some of you will have some working knowledge of. We know that it is upsetting stuff; we are talking about death and dying. For some people it evokes a lot of emotions. If at any point anybody wants to stop or needs a break or support services, we have some of those available. We always say that at the beginning to make sure everybody feels comfortable to say what they want to say.

We are, as we just told you, planning to record today's meeting and we would like to publish the record of that meeting so it can be shared. If there is anything you want to say that you want kept private, please just let us know at the time and that way we will know to either go *in camera* or later on consider taking that out of the record or anonymising it.

Could we maybe just start by doing a whip around of introducing you guys so that we know who everyone is in the room as well?

Mr COMAN: First of all, this is a local authority, and we have appointed members on those authorities. Then you also have council staff and support, so if you want to start with introduction of our members or just go around the room?

Mr CHAIR: As you wish.

Mr COMAN: I will go with the authority, so you have Don Garner, the Chair; Mike Longton and Trish Elmy. We have a couple of apologies from two other local authority members, and another one will be dialling in. We have council staff. I am Cristian Coman, Manager Corporate Compliance, so I look after compliance and governance.

DANIEL: I am Daniel, Finance Coordinator.

LUKE: Luke, General Manager Infrastructure.

Ms HUCKS: Casey Hucks, Council Services Manager, Borroloola.

Ms HADDOW: Cindy Haddow, General Manager Corporate Services and Sustainability.

Mr CHAIR: Fantastic, all right, I think that is everyone.

Mr COMAN: We do not have the chief executive officer. He will be attending shortly.

Mr CHAIR: No worries. All right.

[***Editor's note:*** *much of what the speakers said at this point was indistinct due to movement of items near the microphone. It appears to mostly be off-mic conversations and setting-up furniture.]*

Mr CHAIR: (Inaudible) members of parliament, from the Legal and Constitutional Affairs Committee. We have come down today to talk to everybody about voluntary assisted dying.

To cut to the chase, last year an independent inquiry released this report, which was the 2024 independent expert inquiry Report into Voluntary Assisted Dying. It proposed 22 recommendations and a model for how that might work in the Northern Territory. Every other state and territory in Australia has a VAD law now except the Northern Territory. So we were asked in May by the Attorney-General, the chief law officer, as a committee, to look into this report.

On the back of that report, we produced a consultation paper, which would have been released to you guys before, which is essentially a summary of this and also looking into how we might look into what more we could do to add to this. One of the key things that was drawn out was that there needed to be more consultation in remote areas. People have not really gone out bush as much as we would have liked to find out particularly what Indigenous people out bush might think about voluntary assisted dying.

We have produced that material; there is a short consultation guide and an interim report as well, which is mostly a technical report as well as some media releases that were done. We will leave all this information for you guys, and I imagine you have already received a lot of it in advance anyway.

The crux of what we are here to do today is to ask you how you feel about making VAD legal in the NT, and what thoughts you might have, if you are aware of the support at all. What we are trying to do is if a law gets made in the future, which we will not be in charge of, our job is to simply write a report back to the government to say that this is what we have learned—what might that VAD law look like so everyone in the Territory can access it if they want it and it makes sense.

Anything you want to tell us about healthcare, palliative, government services, anything that interacts with that or this report will be really useful information for us.

I think that is probably enough from me. Did you have anything?

Unidentified male speaker: You keep using the word ‘government’; are you talking about the NT Government?

Mr CHAIR: Correct, NT Government. The five of us are five of the 25 members of the NT parliament. We are from three different parties. We are not here representing the government or a party; we are here working together to see if we can get some good information back to the government and to the parliament to think about.

Unidentified male speaker: Because it was a federal bastard who stopped it last time.

Mr CHAIR: That is right. Quick recap on the federal bastard—no, you are absolutely right. In 1995 the Northern Territory had a voluntary assisted dying law. In 1996 it got overturned by the federal government. In 2022 the federal government decided we could have a new one, and this report was made in the meantime, and now it is up to this committee first to recommend back to the government of the day what we recommend might be a good way forward.

Unidentified male speaker: (inaudible) just let new members, new persons who walked in, just letting you know this is currently being recorded.

Unidentified female speaker: Okay.

Mr YOUNG: And anything you do not want on the record, just tell us and we will take it off.

Unidentified male speaker: Sorry about that.

Mr CHAIR: Not at all. You are absolutely right, thanks. That is really all I have to say. We have lots of nitty-gritty questions, but really we have come to hear what you have to say. We know you have limited time, so it is over to you guys. As Acting Chair, if you want to start, or if council members want to—local authority members, I am sorry—want to start by saying your piece. Anything you want to tell us is useful, including about that bastard in federal.

Unidentified male speaker: Sorry about that.

Mr CHAIR: No, no. That is a good starting point. Were you supportive of the original law?

Unidentified male speaker: Very, yes.

Mr CHAIR: On the basis of?

Unidentified male speaker: Well, a lot of it was political. I think the right people were organising it—that is going to get me into hot water straightaway, by talking politics, but yes. I think it was the right way to go.

I, frankly, did not like the way certain people were crucified—Nitschke, Perron. It was just a bloody—it was a bit of a turkey shoot, really. If this is a bit more sensible, I would be happy with it—I am happy.

Mr CHAIR: Back in the day, the model was a bit different than what is now the Australian standard, so why don't I quickly point out what happens pretty much everywhere now. The rest of the states and territories pretty much have a system where if somebody is over 18 and they are terminally ill, they can go to a doctor—it can be a GP—and if the GP says, 'You've got less than 12 months to live and you can access VAD', then after a waiting period you can go to a second doctor, who has to be able to authorise that, yes, you are definitely terminally ill of the condition that they think. Then, after that, there is a third stage, where a healthcare team of doctors, nurses—a VAD team, essentially—are the people to help people with on-ground support, which is more complicated than it was back in the day, in 1995, but that is the model being proposed here.

Unidentified male speaker: So a lot of people are going to act (inaudible).

Mr CHAIR: I do not know if that is the right way (inaudible).

Unidentified male speaker: By the sound of it. (inaudible) it becomes almost a money grab.

Mr CHAIR: I think it will certainly—what we have heard from the Department of Health is to create a VAD service, you need more money and resources than just using what we have at the moment. That is something we have heard loud and clear. We want to make sure that if there is a VAD law in the future, it is not just for people who live in town, that if people want to access it out bush, they can.

Unidentified female speaker: What is the timeframe between consultations with the GPs?

Mr CHAIR: It is variable and not—can somebody refresh my memory, because that came up earlier today as well. Katie, do you remember off the top of your head?

KATIE: I cannot remember off the top of my head, sorry. Seventeen days, I think.

Mr CHAIR: No, we will have to double-check on that, but the bottom line is that there is the recommendation here for the gaps, but those timeframes vary from state to state. We are not following any one particular model, but what is clear is that you cannot just make a decision today and it is over. There are cooling-off periods, and you can say no at any point.

Unidentified female speaker: Do they continue with their, like, whatever current treatment plan they are on, do they continue with that treatment plan even through that process, that three-step process, they still continue on with that so at any point they can say, 'I want to do (inaudible)'?

Mr CHAIR: There is no reason why they could not, but it will come down to individual people. It is not an either/or. You have the health system, palliative care system and then VAD system, and they all sit separately. The model that is proposed in here is for a standalone VAD system that sits outside of palliative care and health so that people do not start confusing VAD with all of them.

Unidentified male speaker: Do you follow any international, like the Greek—the Dutch? Are you following any specific ideas or plans or whatever? Some of them have some pretty switched-on ideas and (inaudible).

Mr CHAIR: Can you think of any particular ideas?

Unidentified male speaker: No (inaudible) as far as I'm concerned I'm happy with it. But (inaudible) if I see it, I see it, but I do not take it on board. But I know the Dutch are right on board with it.

Mr CHAIR: The simplified version of that is there are other places around the world that offer more permissive VAD laws than Australia does. In Australia, South Australia and Victoria—Victoria did it first in 2017, and Victoria and South Australia have a similar model. Queensland and WA came a bit later. The fastest uptake of VAD in the country is in Queensland. We are still talking about hundreds of people, not thousands of people. New South Wales and ACT did it most recently. Everybody has been learning from the last stage (inaudible).

ACT is probably the only place in the country that is a bit more permissive than the rest. They, for example, do not have a rule that you have to have 12 months' prognosis before death. You just have to be suffering and sufficiently terminally ill that you can access that service. It is worth saying that the ACT one has not started yet; it starts in November. They passed the law, but it takes 18 months to implement.

All of these previous things, including in this report, looked at what is happening internationally, and they settled on a, sort of, this is the Australian standard at the moment, if you like. What this report recommends is consistent, pretty much, with Australian standard, but there are some things, like in Appendix 9 of this it says you have to be aware of what happens to our Indigenous population, culturally aware, and sensitive to all of that. That is part of why we are out here doing this.

That is broadly where it is at. I do not think there is any suggestion that this law would be more advanced or more permissive than any other state or territory necessarily. I am trying to get an answer to your question in the meantime, though. Flicking through things while—if anyone else wants to chip in, just while I quickly find the timeframes between consultations.

Unidentified female speaker: More, really, like, do they get a chance to continue on with the treatment which would change the outcome, and then they (inaudible)?

Mr CHAIR: Yes, is the short answer to that.

Mr YOUNG: There is always that choice to say no at any time.

Unidentified speaker: I am for it. Because we have palliative, a sort-of palliative care up at the aged-care centre, so I visited particularly the last old lady that was in there that passed away, and she was saying that she was just fed up. ‘Now I’m just waiting’, she goes, ‘It’s just so tiring’. It was like, yes, I get it. She decided this was it. You have to have that choice. If you can have a—well, sometimes—choice about everything else, then why not that? Why not?

Mrs CARLSON: I suppose another reason why we are asking remote and coming out to remote is, obviously, you are remote. These services—we are talking about teams and that—will do that. We potentially would not be able to have a standalone space here in this region, but is it something viable that—would you still be comfortable to take the service in the city, where they might have a standalone model, or is it still important—which is why we are here—to be able to provide a service here that you can come back on country and to your local area, that maybe the team does still have to travel back at that point in time?

Unidentified female speaker: I think initially, when they are going through their—in particular with this one person, she was quite happy for the travelling to do the treatments and stuff like that, but she just got sick of it, so then she came back home and just refused to move, pretty much. But then she lingered for months, waiting for it all to happen. I think initially, going away and doing treatments and stuff like that is important, but for them to come back and make those decisions with their families here is probably more important.

Mr CHAIR: Two things on that. The assessment thing, the timeframe, actually is not specified between the different things in this one, but it is in other places, but they are just saying there should be a three-stage process involving two separate assessments. The other thing is the telehealth. Currently, there is a federal prohibition on being able to incite anyone to cause harm to themselves, so you cannot do anything VAD related at the moment, across the whole country, using telehealth. That would necessarily mean that people wanting to access that—in your friend’s situation there—would need somebody to be able to speak to them in person, whether they came here or we took the person up there.

Unidentified female speaker: Yes, the second reason I am asking about those timeframes is because another person who was in respite care, who had decided that this was the end for her, actually recovered.

[Multiple people speaking.]

Unidentified female speaker: Opt-out stages—‘I’m fed up.’

Mrs CARLSON: Opt out at any time. Even at the last minute, you can still opt out.

Unidentified female speaker: She even gave her cars and everything away to family. It was all done. It was, ‘I’m ready to go’, and then she just did not. And then she left.

Mr CHAIR: The key thing in that point—that is the best possible outcome, obviously.

Unidentified female speaker: That is why I was thinking, what was the timeframe between these things? If they end up keep getting treatments, so then if they do get better—'Oh shit, no, I don't want to go now. I'm all good.'

Mr CHAIR: What we found has resonated so far when we are talking is saying, 'Choice and help to finish up'—all right? So we were talking to people out here and they were going, 'Oh okay, yes, I understand that'. At the end of the day, nobody has to do anything, but for somebody who is suffering, this is an option to ease their suffering, but nobody else needs to take it on board in that regard.

Practically, for example, there are—say, Victoria, which started this first, has had about 400-odd people for the last three years, give or take, use it. If you use those same numbers and look at the rest of the country, Queensland's uptake is a bit faster, but still under a thousand people we are talking about. We are probably looking at, maybe, in two years' time if this was to happen, no more than maybe 20 people maximum that we would expect would use something like this.

It would not be like creating a whole new part of their healthcare system for just 20 people if it was not going to make sense. That is why we are thinking about a standalone system that might be based in town, that might fly-in fly-out to help people with this kind of thing. Has anyone else around the room had conversations or has this come up at any point?

Unidentified male speaker: Just in—but not in conversation, but it has come up. Can I ask a question? The certain disparity between Indigenous people and non-Indigenous in respect of passing away—I am talking history now. I have been around a bit. Have you addressed that at all? It is a problem. You probably may know where I am coming from, and you know what I mean, when certain people decide it is time to go, it is time to go.

Mrs CARLSON: Yes, it is probably our biggest burden in the (inaudible) in the last 48 hours. People probably expected us to come out here and it was just going to be no, no, no. But I think what we have discovered in the last few days is that the definitions of 'dying', 'assisted' and 'voluntary' are very different in 10 culturally sensitive places. That is why our conversations the last couple of days have been saying that this could still probably work, but in a different manner. We would not need to have a needle. It is now, how do we help you come back early enough so you can spend time, so you are still making a decision …

Unidentified male speaker: Without fear of …

Mrs CARLSON: … and you are being assisted? Yes. That is why it is really important that we capture that in this document, because I think that was missed—there was a missed opportunity in the first document (inaudible).

Mr CHAIR: Our inquiry is not about replacing everything that has happened in the last 30 years.

Unidentified male speaker: That is fair enough.

Mr CHAIR: This is a final sweep to try to pick up information from places that maybe did not get enough attention in the past. That is why we are coming out bush. We had one day in Darwin, and we will have all the remaining days in regional and remote places, because we are just trying to talk to anybody, frankly, who wants to talk to us.

Unidentified male speaker: What you just referred to, we are not talking about five or 10 years of history; we are talking about hundreds and hundreds of years of history that has been going on forever and a day, is what we are talking about.

Mrs CARLSON: For some people there is another challenge at another level; it is also religion. Some of them live in both worlds as well, so yes.

Mr CHAIR: We want to be respectful of people's views. People will have different cultural or religious perspectives on this as well. What this report suggested was that there was about 75% who would support in the community from the surveying they did for people wanting to move ahead with this. There are lots of different versions of that, but there is the suggestion that more than 50% of people across all states and territories across the country would like laws in this place.

Every other state and territory has one. The question is: should the Territory have a law about this as well? In general, what do people in the room think about whether the Northern Territory should have a law in this area or not? It would be good to hear from some of the reports there.

Unidentified female speaker: Everyone should have a choice.

Mr CHAIR: Are you concerned? Do you have fears at all for what might happen if a law like this was brought in?

Unidentified male speaker: No, not really.

Mrs CARLSON: Do you think it would change the community? Because I know in the past, when it first was, it did sort of divide a little bit, I suppose.

Unidentified male speaker: I think there were changes in the community now; it had nothing to do with that. I mean, there are definitely changes afoot now between different colours—whatever you like.

Unidentified female speaker: Every decision is going to have two opposing sides. I know for one of them, she would have been very happy to have a part in this. Other people may disagree, and they can, but you cannot stop people from having a choice. I would.

Mrs CARLSON: Being in a remote area, do you think there would be any limitations? What limitations do you need to consider, I suppose? We flew today and it took a long time on a plane, so …

Unidentified male speaker: I just wonder about the teams you have, the VAD teams, whatever you called them. They are going to be based in the larger centres?

Mrs CARLSON: That is what the current report says.

Unidentified male speaker: Remote areas seem to always be almost forgotten about and just an afterthought. We have people here who maybe want to uptake on VAD process.

Mr YOUNG: That is part of the consultation.

Unidentified male speaker: Part of it, I think, is they should be able to do that at home, and that is really important. But is it going to be geared up for that to happen? Because it may be—I do not know what length the process is, but if they are on the wagon to go through the VAD process, are they going to have to travel into town all the time to meet with the team or what?

Mr YOUNG: We will be looking at that through the consultations and whether someone wants to pass away at home, in Borroloola, for example, and how that may look when a nurse comes out to be able to help administer the medicine for someone to pass away at home, whether it is doctors. That will come out in the report ...

Mrs CARLSON: We are assuming they are not going to keep the medication here.

Mr YOUNG: If people want to take voluntary assisted dying in their community as well, that would be some of the restrictions we have with resourcing as well. That is something we will have to think about. We have a lot to think about.

Mr CHAIR: Your point is very—this is exactly the point, right? If somebody here wants to use it, can they, and how can we make that happen? As we just said, we are probably looking at less—in terms of process, just to answer your question, if we now have a month on the road collecting data like this, then we will be reporting back to the parliament in September, and then we will see what the government does with it. Then the government can decide to ignore it, make a law out of it—all things are possible still.

Then it would probably take 18 months to implement, which is what happens everywhere around the country. Usually, you get 18 months to put it into practice. That is 18 months of figuring out the fine-tuned details of how to make sure people can access it. The thinking at the moment, as best we know, is that if we are only talking about 20-odd people a year in the Northern Territory that might, statistically speaking, take this up—we are thinking about people who have terminal illnesses, who are in palliative care, across everywhere then it does not justify having multiple teams of doctors and nurses all over the Territory just for 20 people.

The idea would be that you would probably have some sort of standalone unit and they would be based probably in Darwin, you would think, and they would fly-in fly-out to do whatever work was required, which also included things like we had questions about—we do not want drugs stored in the community, dangerous drugs. That has to be thought through in these things as well, and they are suggesting that those kinds of things would be consistent with other protocols kept in the hospital, kept in secure spaces, kept according to the Poisons Act and so on and so forth.

We are trying to make sure that in introducing law, you do not do new harm, of course. The idea of this is to create a compassionate law that stops people suffering or minimises their suffering. For some people, that might mean actually ending their life, for some people it might mean helping them to finish up their life on country. There is a range of interpretations here, but we do not want the bush or regions to be ignored. That is why we are out here.

Unidentified female speaker: Would it be worth giving opportunity to regional nurses that are already out here to get that sort of training and be a part of that process? Then it is a double-edged sword; they are out here already doing nursing, and if that opportunity comes up (inaudible).

Mr CHAIR: I think that would definitely be part of it (inaudible).

Mr KERLE: We have to be careful with that one, because if people are involved in someone passing away, there might be some confusion and blame inappropriately placed. We have heard some testimony that we need to be really careful in that space, so we might need to separate health services in community and how this would operate.

Mr CHAIR: The other more general point is that even medical practitioners—whether they are doctors, nurses, whoever they are—do not have to participate in this. There are some medical practitioners who will conscientiously object and not want to be a part of it, so that is accounted for and allowed for. In some states and territories, doctors and nurses are not allowed to bring up the conversation with patients. In other states and territories, they are allowed to say to a sick patient, ‘Have you thought about this?’ Do you guys have a sense of how you feel about that?

Unidentified female speaker: I think it will be an incredible journey to have a discussion with people. Not a lot of people will realise that they have (inaudible).

[Multiple people speaking.]

Unidentified male speaker: Following on—we haven’t got a black fella here in this room (inaudible – multiple speakers). You know that I am not being rude.

What happened with Mabunji? Did you have heaps of people there? There are 500, 600 or 700 blackfellas in this town—Indigenous people, for want of a better word—how are you going to get through to them?

Mr CHAIR: You start with whoever will talk to you.

Unidentified male speaker: I am not being silly. They are the people who should be spoken to and you (inaudible) them tomorrow.

Unidentified female speaker: The consultation process is always like this. You always have the stakeholders who are having the discussion, and then we talk about how best to introduce it to the community and get them to be on board. That is the second part of the whole thing, but if we do not know what we are talking about in the first place, we are not going to roll it out and not going to be able to discuss it very smartly with them. But you are right.

Unidentified male speaker: What you are saying is we have to go back to Roper Gulf, ask them for a pocket of money and go out and talk to all the people in communities, because that is the only way it is going to get through.

Unidentified female speaker: I never actually said that. I do not know how that is going to (inaudible).

Unidentified male speaker: No, I know you didn’t. I’m putting words in your mouth.

Unidentified female speaker: It is not council’s responsibility to have consultation.

Unidentified male speaker: I realise that. I am being facetious, but how do you get through?

Mr CHAIR: I think it is a fair point in general, and what I would say in fairness is that we have limitations and time limitations. We are lucky to have our parliamentary staff who are doing the best they can to connect us to as many places, to as many people who will talk to us this month. Yesterday we were in Ngukurr, today we are here, next week we are in Numbulwar and Papunya and Alice and so on and so forth it goes.

You can never cover everyone, but you try to cover a representative spread of places, people, cultures, locations and places to get a sense of what we can do. If this goes forward, as we say, all we will do is produce the report, which will go to the parliament later this year, and then the government will consider how it will move forward with it. It is the government's responsibility, the Health department's responsibility; they are the people in charge of implementing it. Whatever it might be, they carry the burden of communication.

Unidentified male speaker: Have you considered putting out, for want of a better word, a flyer? I am serious. You are laughing at me.

Mr CHAIR: No, no, it is fair.

Mr KERLE: I am laughing because we do have a flyer. We have a consultation paper and a flyer, and we are trying to translate into as many—so all of this stuff (inaudible).

[Multiple people speaking.]

Mr CHAIR: Folks, can I just say, you have all been really generous with your time. We need to cease recording at this point so that we can open the meeting.

Committee concluded.
