

The committee convened at 1.14 pm.

INQUIRY INTO VOLUNTARY ASSISTED DYING Pulkapulka Kari Flexible Aged Care

Mr CHAIR: We know you have plenty of other things to do, so it means a lot to us that everybody is willing to take time and have a chat with us.

Before I say anything else, on behalf of the committee we want to respectfully acknowledge the traditional owners of the land of this country and we pay our respects to elders past, present and emerging.

We are genuinely grateful, as a committee, to be able to come out and have conversations with everyone out here, to actually hear where you are what you have to say, rather than just relying on submissions on paper that end up back in Darwin.

My name is Tanzil Rahman. I am one of the five members of the Northern Territory parliament. Five of us are on the Legal and Constitutional Affairs Committee. I am the Chair of that committee. Four of us were able to make it out today. I will let them introduce themselves.

Mrs CARLSON: I am Oly Carlson. I am the Member for Wanguri which covers the suburbs of Wanguri, Leanyer and Muirhead which, if you are not familiar with the Darwin area, is in the northern suburbs next door to the Casuarina shopping centre and Royal Darwin Hospital.

Mr KERLE: My name is Matthew Kerle. I am the Member for Blain. I drove past Blain Street here and I was like, 'Hey!'

[Multiple people speaking.]

Mr KERLE: That is a couple of suburbs in Palmerston—Woodroffe, Moulden and Bellamack. There is a lot of public housing in my area, so I do get people at Warumungu and people from around here who come and stay with family in my area. That is about it.

Mr CHAIR: We also have Georgia Eagleton who you have been talking to and who has helped organise our logistics; Caroline Williams down the back; and also Katie Helme. These guys work for the Department of the Legislative Assembly, and they have been helping us with the inquiry to do all the heavy lifting, the hard work, all the logistics and, as you can see, recording and whatnot here today as well.

I should start by saying that we have come here specifically to talk to you guys today about voluntary assisted dying (VAD). We know that it is something that can be upsetting for a lot of people to talk about, so we always say to everyone—no matter who we are talking to, whether they are doctors, nurses or out in bush—if any of this makes you feel upset or you want to take a break, just let us know and then we can do that. We also have support services available that our staff members can help with if you want to take a break or if you need anything like that. We always say it because we know it is difficult subject matter we are talking about.

The specifics of what we are talking about, I think you guys will know a bit about it already. VAD is essentially helping somebody who is terminally ill, dying, to take a prescribed substance and help them, if they request it, to hasten their death in a manner and time of their choosing. We are going to talk about the details of all that and see how you feel about lots of the issues surrounding it.

Before I say anything else, I should also mention that we are recording this session, and we are doing that because we are gathering all the things that we learn as evidence that will contribute towards the report that we want to write. If there is anything you say today that you want kept private, that you do not want on there, just tell us and then we can remove that part. Because we are talking about death and dying, sometimes people have personal stories or personal medical histories or it could be anything that they may not necessarily want recorded, so if at any time you want anything excluded, just let us know and we will make sure that part is excluded from the transcript of what we are talking about.

We are going to just get all your names on the recording for a second and just get everyone to introduce themselves so that when we talk later on it is easier for the people who transcribe it to know that it was Bob who said whatever. Can we go around the room maybe? If you could just state your name and what you do here.

Mr RAIWALUI: My name is Peni and I am a leisure and lifestyle.

Mr CHAIR: Leisure and lifestyle—great, Peni.

Ms SILIBAU: My name is Sophie and I am a leisure and lifestyle officer.

Mr CHAIR: Fantastic.

Ms BOROTU: My name is Mijina and I am one of the registered nurses.

Ms PENEZ: My name is Loida and I am a community nurse.

Ms FORSYTH: Tania, nurse/trainer.

Mr CHAIR: Did you say traitor? Trainer, not traitor—well, that is exciting; that is not something we have heard before. Just to clarify, RN, EN, nurse practitioner?

Ms FORSYTH: EN.

Mr CHAIR: EN, okay.

Ms FORSYTH: This is Lavenia, she is our nurse (inaudible).

Mr CHAIR: Thank you for joining us, Lavenia.

[Multiple people speaking.]

Mr CHAIR: Lavenia, could you just state your name for the microphone.

Ms ALEAMOTIA: My name is Lavenia Aleamotia. I am a registered nurse here at the home.

Mr CHAIR: Thank you so much.

Mr YOUNG: Sorry, everyone; I just had to take a phone call from my partner.

My name is Dheran Young. I am the Member for Daly and the Deputy Leader of the Opposition, so I am part of the Labor Party and also a committee member. The communities I represent are Wagait Beach, Dundee, Berry Springs, Pine Creek all the way out to Daly River and Wadeye.

Mr CHAIR: Fantastic.

Why don't I just introduce what we are talking about so that everyone is on the same page and then we will go from there.

The story of all this starts in 1995 in the Northern Territory when a law got passed to allow voluntary euthanasia; what we now call voluntary assisted dying. That law was around for one year before the federal government intervened to stop that law, basically. They made a determination that the territories of Australia should not be able to make laws about voluntary assisted dying.

Fast-forward 20 years, in 2022 the federal government overturned that and allowed the territories of Australia to make laws about voluntary assisted dying again. In the meantime, every state and territory in Australia, starting with Victoria in 2017, has now introduced and passed a voluntary assisted dying law. Every state has one and so does the ACT now. The ACT's one has not started yet; it starts at the end of this year. They passed a law, but it is not operational yet.

Last year an independent expert panel was put together to draft this report. This report was written by doctors, lawyers, community representatives—a range of expert independent people commissioned by the former government to make a report about voluntary assisted dying in the Northern Territory, whether there was support for it, how it could work, whether we should do it and that sort of thing.

The current government, the new government, asked this committee to look into this report and its recommendations and its model to see whether or not we could add any extra value, particularly by coming out to remote areas and talking to people away from Darwin, Alice and the major centres.

Over the last month we have been going out to communities, as best we can, and as many places as we can, to talk to people about voluntary assisted dying, but also to talk to them about the things that interact with VAD. We know that when you have conversations about VAD you also end up having conversations about palliative care, aged care, the health system generally and interpreters—all sort of things like that. If there was a voluntary assisted dying law in the future here we know that it would be a new thing to add to all of those systems, so we want to understand what things are like now and how it might all fit together as well. We have come out, basically, to ask you guys some general questions, but also to hear your questions and see if we can provide any answers and information for anything that we might be able to tell you.

It is important to say we are not here to pass a law or even write a law; we are here to write a report. We are here to gather information, listen to you guys, learn and hopefully put as much of that together as we can in a report and present that to the government. Then the government will decide what to do next, whether there will be a Bill and then maybe a law and whether this will happen in the Northern Territory as well.

Can I maybe ask any of you, just as a starting point, to tell me if anyone has any thoughts or feelings about VAD? Are you for it? Are you against it? Do you know anything about it? Do you have any reflections on any of that, if you want to start?

Ms FORSYTH: Yes, I can.

Mr CHAIR: Yes, please.

Ms FORSYTH: I am a Victorian, so I am well aware of this.

Mr CHAIR: Okay, great.

Ms FORSYTH: We have these things in Victoria (inaudible) stuff. Yes, I am for it. You see I have lost a child, so I know what it is like to lose and watch people in pain. Yes, I am for it.

Mr CHAIR: Thank you for sharing that.

Ms FORSYTH: Victoria had it for two years or three years ...

Mr CHAIR: In 2017 they passed the law, so it has been a while.

Ms FORSYTH: It has been a while. I remember attending some things (inaudible). My understanding is we have nothing to do with it anyway. (inaudible) GP and inquired anyway. We were told not to even bring it up ...

Mr CHAIR: Yes.

Ms FORSYTH: ... if you come to us we were just (inaudible) clinical nurse manager and then pass it on. Then it was dealt with doctor and patient.

Mr CHAIR: That is a very significant point you raised. As you pointed out, other states and territories already have this. We are lucky that we can hopefully try to learn from some of that and figure out if we could pass a VAD law in the Territory that would work for the Territory, knowing that 30% of the population is Indigenous, lots of people are remote—the circumstances are obviously different here than elsewhere.

Victoria, when it first started this process, recommended that medical practitioners could not initiate the discussion about VAD; they were prohibited from bringing it up. Now, other states and territories have decided differently and they allow all healthcare practitioners to initiate the conversation, provided they also talk about all the other options—palliative care, healthcare—and that is not the only thing.

This report recommended that if the Northern Territory had a VAD law that practitioners here also should be able to choose to have that conversation, if they want to be part of the system, but there is no obligation for anyone to have to do that either.

The first key word in all of this is 'voluntary'—choice. This is not about forcing anyone to do anything, which means not forcing a person who does not want to have it but also not forcing a healthcare provider, an organisation, a nurse or a doctor—they do not have to be part of the system either if they do not want to. People should be able to conscientiously object.

We are happy to hear from people who are for this, against it, any concerns they might have. From your experience in Victoria, are there things that came up that you remember that were problematic?

Ms FORSYTH: There were a lot of boxes that had to be ticked to actually qualify to even do that. It could be at home or it could be in a hospital setting, a care setting. That arrives in a box and it was done between the patient and family member or doctor, whoever was there at the time. We were not allowed in there until they passed away. That is all that I am aware of. You had to tick all the boxes for the dying and stuff, like, 'I've got cancer and I'm going to die' or 'I'm not having the treatment so I picked it'. You had to go through a whole lot of stuff to ...

Mr CHAIR: Correct.

That is probably a good opportunity to talk about the model that is proposed in here and what boxes you do have to tick to access this. The Victorian one was first and it was a pretty high bar; you had to tick a lot of boxes to access it. Now, each state and Territory has a similar model, but some places have started to get a bit more permissive or provide a little bit more flexibility to allow people to take it up a bit more easily.

In Victoria there are about 400 to 500 people a year who have been using this. In Queensland the numbers have been going up a little more because it is a little bit easier in some ways. In the ACT, which has not even started doing it yet, some of the rules are different again. In the ACT you do not have to have a 12-month prognosis of life span. In other places, doctors will have to specify you are dying within a year or, in some cases, in fact six months before you can qualify. In the ACT model, for example, the 12 months they have decided is unnecessary. There is a slight variance.

What I will do is I will just talk you through the model that is in here. We will leave these documents with you and you can find this online. I think on page 56 of this—which I now cannot find, but anyway—there is a flow diagram of basically how it works.

In a nutshell, and remember it varies slightly from place to place, the first step is if you are somebody who is terminally ill, over 18, fully cognisant and can still give consent—so you cannot have dementia and it cannot be in an APP (advance personal plan)—if you are in a position to give consent yourself, you can approach a first person, which is a doctor, to ask whether you qualify for this. If they say no, then that is the end of it. You can appeal to an appeals board.

If they say yes, after a waiting period, which is usually around nine days, sometimes a little bit shorter in some places, you then go to a second stage. Then you have to ask a second medical practitioner—the standard of medical practitioner varies a little bit in some places. In some places it is like a specialist; in some places it can be or another GP. But a second independent doctor has to sign off and say, 'Yes, you are an eligible candidate for VAD'.

Then there is a third stage, which is a person has to be able to provide written consent and there has to be some witnesses to that. Those witnesses have to be independent witnesses, not necessarily people who are beneficiaries of a will—that sort of thing—or a power of attorney, but somebody separate to all of that. There are slight differences from place to place.

Only if you can cross all three of those thresholds, then the last stage is that a medical team, usually led by a doctor but sometimes led by a nurse practitioner as well, is allowed to help a person with actually administering a VAD substance. In most of these places there is an option for somebody helping you to administer or the option of self-administration. If it is self-administration, in some places you have to be supervised; in other places, it can be unsupervised, but a contact person is allowed to be given the drugs essentially that a person is to ingest. Most of the time when it is self-administration we are talking about, it is an oral ingestion, and when it is an IV situation, an injection situation, then it is usually a medical team that helps out.

That is the rough process that pretty much exists everywhere in the country, with some small variations here and there like on prognosis, where the drugs are stored—small technical but important details.

What we are trying to do is think through how would this work in the Northern Territory. For example, let us take where the drugs would be stored. We know that it is tough to store medications across the Territory everywhere, so the suggestion in here, for example, is that it is probably likely that any VAD substances will be centrally stored and when they are required, they would be brought out to wherever it was required. You would not have dangerous drugs in a community just lying around as it were, not that anything is lying around, but you get my point—right?

The other thing to mention in all of this is assistance. We are trying to provide people the opportunity to have a choice. We know that, particularly out in Indigenous communities—we have been going out there—it is not that everybody necessarily wants this for themselves, but we were also trying to test that if other people have this, do you have any objections, how do you feel about that. The phrase we keep coming back to is ‘help and choice to finish up’. When we say that to people in remote communities, a lot of them have said, ‘Yes, we would like more help and choice to finish up, particularly out on country’. Some people do not want to die in hospital necessarily.

That is a useful point for me to ask you guys about what you do here because it is really good for us to know. What services do you currently provide? What could be done better? Do you have palliative care services here? Do you have enough aged-care beds? How about some of you fill in the gaps for us?

Ms BOROTU: Yes, we have palliative care services. They either pass away here or in the hospital or sometimes they get transferred to Alice if something is going wrong more seriously to investigate and they then pass away.

I am not very familiar with VAD. I worked in Queensland and now NT; I have never been involved in it. I came here to learn as much as I can, definitely. I am not sure how I can see it fit here because already it is quite an issue to discuss death and dying. I would love to know how that would sort of work here.

Mr KERLE: With your patients, when you have to discuss death and dying, what does that look like? Do you have to have a translator? Are there cultural things you have to ...

Ms BOROTU: Since I have been here I have not discussed it with them. I have been here eight-and-a-half months with a bit of a gap in between. No, I have not. I have not had anyone palliative while I have been working, so I have not been that involved during the dying process here in this facility. I cannot speak really on that. But we have had people pass away recently.

Mr YOUNG: What is the capacity for palliative care here?

[Multiple people speaking.]

Ms ALEAMOTIA: In here the process, like if we know that someone is really (inaudible) end of life, there is always a meeting between family members and doctors and nurses and clinical nurses prior to when anything happens. In saying that, before those things happen we have been prompted with what we have to do. We go (inaudible) with the doctors a status report about (inaudible), so where you have to administer here.

Once the resident passes on it is our responsibility here as a nurse to actually wrap up the body and call the ambulance paramedics to come and take the body away. But sometimes if it is—what is the word? The police come ...

Mr KERLE: Coroner?

Unidentified speaker: Coroner.

Ms ALEAMOTIA: Coroner’s case. We just recently had one because he passed here recently unexpectedly. If we know that someone is on palliative care prior to that it is a (inaudible) process. With the information that I know, I do not know if really it is going to be fit here in the Northern Territory.

Ms PENEZ: We normally have the palliative care pathway to follow up. That is our policy.

Ms BOROTU: I think it is on a monthly basis or something like that, the palliative care system ...

[Multiple people speaking.]

Ms BOROTU: Every six weeks, yes, so they follow up with people who are already on palliative.

Ms ALEAMOTIA: (inaudible) we can always call them for anything if we are in doubt in regard to what is going on (inaudible) that particular resident.

Mr CHAIR: We have not had a look around yet, but this looks like a lovely facility. Do you ever have any resistance to people coming to this facility? Are they scared to come here for treatment? Are people happy to come here?

Ms PENEZ: Most people want to come here so that we can look after them.

Ms FORSYTH: We have got a waiting list.

Ms ALEAMOTIA: We do not have enough beds ...

Mr CHAIR: Yes.

Ms ALEAMOTIA: (inaudible) waitlist are there, but there is not enough beds here for the facility to take all those who are on the list.

Mr CHAIR: Gotcha.

Mr YOUNG: Do you have dedicated palliative care beds? Is it completely separate? Or is it just the case ...

Ms PENEZ: No.

Mr YOUNG: If someone is coming from Alice Springs, say, from palliative care to come pass here, it would depend on the capacity at the time?

Ms PENEZ: It is just if a bed is available. There are no specific beds for palliative care.

Ms FORSYTH: Can I just interrupt for a second?

Mr CHAIR: Please, yes.

Ms FORSYTH: Irene is our facility manager.

Mr CHAIR: Hi, Irene.

Ms SNELL: Sorry I am a bit late.

Mr CHAIR: Not at all. Thank you for joining us. We are really pleased.

Ms SNELL: I am sure you have been made welcome ...

Mr CHAIR: Everyone has been very welcoming. Thank you, we appreciate that.

Matt, go ahead.

Mr KERLE: Following up on that, when people are getting towards the end and they are starting to deteriorate, are there any discussions? Does it happen often that people are there from a homeland or a community that is further out, where they withdraw from care and go back out to community to finish up, or do they usually just pass here?

Unidentified speaker: Have you guys done ...

Ms SNELL: It depends on what their wish is.

Ms FORSYTH: A couple of weeks ago, Jeffrey Taylor (inaudible). They suffered and had been unwell for a while. I said to the girls—Peni, I am sorry—we need him back to country so that he can go back there. They arranged it ASAP, took him out there and spent a happy party(?) out there with the family. Then came back and then peacefully went to sleep.

Mrs CARLSON: He actually passed away here?

Ms FORSYTH: Here.

Mrs CARLSON: But had time back on country.

Ms FORSYTH: Correct. Probably how many days, Soph?

Ms SILIBAU: About a week.

Mrs CARLSON: About a week?

Ms FORSYTH: Yes.

Mr CHAIR: Was that using the visit to country service?

Ms FORSYTH: We did it. Our lifestyle organised it. Then we organised the (inaudible) with all the family. Irene approved it. We just took it to Irene and she approves what we need to do.

Mr YOUNG: How does that look for you? You obviously physically drive out there. Do you stay with the person for that week that they ...

Ms BILIBAU: No, just a one-day trip.

Mr CHAIR: It was just a one-day trip.

Mr YOUNG: It was just a one-day trip, so just there for the day.

[Multiple people speaking.]

Ms FORSYTH: They left at 8 am and came back at six that night.

Mr CHAIR: That was ...

Ms FORSYTH: Took us to Elliott.

Mr CHAIR: That was not using visit to country, the ARRCs program? That was separately? You guys just ...

Ms FORSYTH: It is visit to the country.

Ms SNELL: ARRCs has got a visit to country. They have got the whole (inaudible) for that. Because we (inaudible) more difficult, they do not service us the same (inaudible). It is not that they do not want to, it is just staffing issues and all that. So we do our own visit to country.

Mr CHAIR: Gotcha.

Ms SNELL: We do Elliott. We do Ali Curung. We have been to Alice Springs (inaudible). Whatever the need is we do try to accommodate it.

Mr CHAIR: In that situation have you ever taken someone out to country, not just for a day trip but to actually take them out to finish up?

Ms SNELL: No, because we do not find that they want it here. I know in Docker River and in Mutitjulu they do and I think it is because there is a stronger connection there. Tennant Creek has not got that strong connection to culture—that is what I found—so we do not get those requests.

Mr CHAIR: Okay.

We have heard a mixed bag. Obviously, all communities are different across the Northern Territory. We know that Indigenous people across the Territory are not one homogenous entity. We have heard a lot of people talking about wanting to come back to finish up on country, so that is why we are asking these questions. We are trying to get a sense of whether there is demand for that here or not.

Ms SNELL: When they normally say that they are coming back to country to Tennant Creek, normally they would want to die here because this is their home. Like I said, Tennant Creek does not have that strong cultural connection where people actually want to go out to the bush and die there. I do not know why; it is just one of those things in Tennant Creek that we have found, maybe because it is a little city, so they are disconnected a bit from their cultural things.

Mr CHAIR: What about people from homelands who have come in here? The same sort of thing you have found, that they tend to not want to go back?

Ms SNELL: Because we are limited, so we only serve the Barkly region. We do not have people from homeland coming here.

Mr CHAIR: Your catchment area extends ...

Ms SNELL: Our catchment area is just Barkly—in Barkly up until Ali Curung. We do service Epenarra for respite and for admissions, but we would not take clients back to Epenarra.

Mr CHAIR: Okay.

You said you could use some more aged-care beds out here. We could hear that loud and clear. Palliative care comes out here every six weeks or so. This is the most nurses I have seen in a facility for a long time, so congratulations on that.

Ms SNELL: Yes, please tell my staff because they think we are understaffed. I always tell them that my ratio is fantastic.

Mr CHAIR: I am not saying you are not understaffed; I am sure you could use extras.

[Multiple people speaking.]

Ms SNELL: (inaudible) is very good. I come from Western Australia. I have worked all over and I have never come across a facility with such a good (inaudible).

Mr CHAIR: I am delighted to see that in this place I could be like ...

Ms FORSYTH: We need a new facility. We have got the land, we just need the funding for a new facility.

Mr CHAIR: That is interesting. Have there ever been discussions about that or is that an ongoing discussion?

Ms SNELL: There is. We just need someone to give us the money.

[Multiple people speaking.]

Mr YOUNG: Your local member is the health minister.

[Multiple people speaking.]

Ms SNELL: (inaudible) You know what, I am not sure why we had two visits (inaudible) because Commonwealth—there is just a disconnection with Commonwealth and what the people on the ground actually want. We are desperate for beds, and why the Commonwealth will not expand our 23(?) beds.

Mr CHAIR: Just on that, I want to clarify because you missed that part when I was saying we certainly do not want to promise the Earth and not be able to deliver anything. To be very clear, we are a committee of the parliament. Our job is just to write a report and give it back to the government and then they will decide how to go forward with it. But we hope ...

Ms SNELL: Tell them that you know there is a demand because people actually want to come here with the (inaudible).

Ms PENEZ: Yes, it is huge ...

Mr CHAIR: That is exactly—you took the words out of my mouth. The point is that we would like to write the best report we can within the time that we have available and represent whatever we are hearing in relation to aged care, palliative care and, of course, VAD itself. The reason we are interested in all the interdependencies is we know wherever across Australia you introduce a VAD law, it ends up that the need for palliative care starts to go up as well. We want to make sure that we do not just talk about VAD and do not mention palliative care. Then when you are talking about palliative care you have also got to think about the broader healthcare system.

In this place here, what has the retention been like of your nursing staff?

Ms SNELL: At the moment I have got a really good retention, but it is remote and people generally do not stay more than three to four years.

Mr CHAIR: That is still pretty good ...

[Multiple people speaking.]

Mr CHAIR: I am not trying to make your staff all leave.

Ms SNELL: We have good bribing(?) techniques here.

Mr CHAIR: Good.

Ms FORSYTH: We start off at agency and then she bribes us and ...

Mr CHAIR: Gotcha.

[Multiple people speaking.]

Mr CHAIR: That is fantastic. We will have to find out what you are bribing them.

Ms FORSYTH: I remember walking in here—it has been nearly two years since I joined and came to ARRCs. I remember walking in on my first day going, 'I think I could make this place my home'. I do not know why. It was clean. Irene, you run this place how I would run it. My morals are her morals. I do not cut corners. It is how I want people to be treated. I have got work with the First Nations people. I have because I have been a similar(?) nurse for five years. I will not go anywhere else because I think they miss out big time, so I like to be the eyes and ears for people. Just ask Irene; I am always in the naughty chair going, 'Ah! We need this. We need that.' Fight for their rights.

Mr CHAIR: That is wonderful that you are happy in this workplace and that you guys have such good retention. It is really encouraging for us when we see a facility with happy campers doing the best they can and doing good work.

Ms SNELL: Feed(?) them. We have lots of parties.

Mr CHAIR: Well, that helps too.

[Multiple people speaking.]

Ms SNELL: It is the little things because we are all—90%—are not born in Australia, so we have to get together and make this place home so we do not miss too much. We celebrate cultures. We celebrate everything.

Unidentified speaker: She is actually a mum to all of us.

Mr CHAIR: Everybody wants a good boss—100%.

Ms SNELL: I would like to think that I was trained by bosses that I would never like to be like that. They taught me what not to be.

Mr CHAIR: We were in Alice Springs last week and the Alice Springs Hospital provided us with a written submission. Our written submissions are still available until the end of this week in case any of you want to also write anything down. There is also a VAD hotline you can call later and just say what you want to say if you want to say something outside this meeting. The reason I bring up the Alice Springs submission is because some of the Alice Springs palliative care team, as well as the submission generally, indicated to us that they were sort of supportive of VAD, but if it was to become a law and if it was to be implemented they would not want VAD services to happen in their facility because already a lot of people are suspicious and nervous about coming to visit them. If it happened, they would want it to happen somewhere else.

It sounds like people have passed away here and do on a reasonably regular basis—on the right sort of regularity. Would you have a problem with VAD being practised on this premise if somebody wanted it?

Ms SNELL: I think it is the word that is wrong because when you talk about VAD, then immediately you are helping to kill them. That is the perception of everybody.

ARRCS is a religious organisation, so we would not support that because we fall under UCH.

Personally, I am also not in favour of VAD because of my faith, but if someone wanted I would support it.

Mr CHAIR: In that situation, let us say somebody comes to stay here and, for whatever reason, they are terminally ill and they have chosen and they qualify and they are eligible, would you personally mostly likely opt out of those discussions? Would you be ...

Ms SNELL: I would, but I would find someone who is actually comfortable doing that.

Mr CHAIR: That would be okay with you still?

Ms SNELL: That would be okay as long as that other person is comfortable. You have got to be comfortable because afterwards you have got to live with yourself.

Mr CHAIR: Of course.

Ms SNELL: Saying that, I would like someone when my time comes to actually do that for me because I would not like to suffer.

Mr CHAIR: Yes. A lot people will say in their written submissions that they oppose it on cultural, religious, whatever reasons. The majority of the people who write submissions to us saying that they would like this to happen tend to have a personal experience tied to it. They have seen someone suffer or die, or they themselves are ill.

This is about a choice for people that they could take or not take, but at least provide them a choice in the case where it is obviously passed. A lot of people would not necessarily choose VAD, but sometimes it gives them comfort to know that the option exists, at least, for later in life.

For argument's sake, if we did have a situation here, a palliative patient who wanted to pass here, if they qualified through the process we discussed earlier, then would a team remotely coming in to help in the final stages be something that was acceptable in this premise?

Ms SNELL: No, because of ARRCS.

Mr CHAIR: Is that ARRCS' uniform position?

Ms SNELL: It is ARRCS' uniform position.

Mr CHAIR: Across all its facilities?

[Multiple people speaking.]

Mr KERLE: You said before ARRCS is a religious ...

Ms SNELL: Yes, they fall under UCH—Uniting Church.

Mr KERLE: Okay; I did not know that.

Ms SNELL: For that reason, I do not think they will accept ...

Mr KERLE: Yes.

Mr CHAIR: In the palliative setting, though—obviously there is a room full of nurses. A lot of you would have administered pain relief to help people. Where is your pain relief medication stored here? Is it secure here?

Ms SNELL: It is secure.

Mr CHAIR: You have never had any issues with it being broken into or that sort of thing?

Ms SNELL: No. It is in a secure S(?) legislation.

Mr CHAIR: In a lot of places even with the legislative protections, unfortunately, sometimes there are incidents. It is not wholly secure. But it is great to hear that here there have been no problems in that regard.

Ms SNELL: We follow the law to the letter.

Mr CHAIR: I am sure.

Here you have lots of practitioners, ENs, RNs practitioners. Are you all qualified to enable to provide pain relief for palliative patients?

Ms SNELL: Yes.

Mr CHAIR: There has never been any issue with any of that here in terms of access to what you need?

Ms SNELL: We have actually got a really good reputation for (inaudible).

Mr CHAIR: That is fantastic.

What is the occurrence of doctors coming out here and working with you on that?

Ms SNELL: Twice a week we have got (inaudible).

Mr CHAIR: There is a GP and that person is local?

Ms SNELL: Anyinginyi.

Mr CHAIR: Say that again, sorry?

Ms SNELL: Anyinginyi, the ...

Mr CHAIR: Anyinginyi, of course.

Ms SNELL: But we also have a really good relationship with the local hospital. They are very supportive. They are just a phone call away. They are so supportive that I have got them on speed dial. They would come in and come and help, and we have not got any agreement with them. Everybody in Tennant Creek just does things because we want to do it for the residents. That is the type of relationship we have.

Mr CHAIR: It sounds like this is a trusted facility, trusted staff ...

Ms SNELL: It is.

Mr CHAIR: ... which is very important.

Everywhere we go is different. In some places there is a fabulous school, but no clinic. In other places there is great clinic, but no school. In another place there is a council office, but no clinic—you know. It is difficult to find—Tennant Creek is bigger, we know, than a lot of the places we have been to. It makes sense that there would be more services, but that does not necessarily mean that they all cooperate or are working well.

Ms SNELL: Let me tell you when I started here they were not cooperating.

Mr CHAIR: How long ago was that?

Ms SNELL: Six years ago. Horrible stories (inaudible). They would say, 'People are getting killed at Pulkapulka Kari. The hospital, I remember when I reached out to them to come and collaborate, they said no. So, we have come a long way.

Mr CHAIR: Without wanting to impugn yourself in any way, can you give us a definition of what 'horrible stories' mean?

Ms SNELL: They would say to me that they had never felt (inaudible) they come here. They have always been dismissed when they come here. There is no open disclosure, so people think maybe not get killed, but people have (inaudible) because people come and they die and there is no openness, discussing with the family, involving the family, why they died and everything that has been done. That is important because you need to earn their trust.

Mr CHAIR: That communication that you have improved over time, has that involved interpreters and translators as well? How have you improved that communication?

Ms SNELL: Just by reaching out to higher authorities. I have been banging on doors. I have been to politicians. I have been all over. Everyone who has a say in Tennant Creek I have approached.

Mr CHAIR: It is great to hear things have improved over time. If things could improve further, what are the next steps? What is on your wish list or dream? What is on the bucket list for what could be done here?

Ms SNELL: My bucket list is that we work closer together so that we can share resources because we are ARRCs, we are not-for-profit. They are NT Government. The hospital is NT Government. The clinic is operation, so we need to share resources, pool together and (inaudible).

Mr CHAIR: In the past or even now, have you been at times working at cross-purposes? Have you seen duplication ...

Ms SNELL: We do. We share how we do things, but it is not in an agreement. It is not by the book or whatever; we just do things together.

Mr CHAIR: Off-book things happen?

Ms SNELL: Off-book things happen.

Mr CHAIR: Again, without wanting to impugn yourself, can you give us an instance? We are trying to find where the gaps are, if you know what I mean.

Ms SNELL: With COVID we could just call the hospital and say, 'Can you spare us this?', and they would do that. We could call the (inaudible) at the clinic, and nothing is give it back, return—whatever—buy one, it is just sharing ...

Mr CHAIR: Yes, resource sharing.

Ms SNELL: When we had the smoke issue, we had the fire, I was getting inhalation for puffers from the hospital from the (inaudible). Everybody said, 'What do you need? We will share.' That is what has been happening.

Mr CHAIR: I already mentioned—because you came slightly late—we are recording today's session to use the transcript as part of the evidence for our report. If there is anything you say that you are uncomfortable with or you want kept private ...

Ms SNELL: No, no ...

Mr CHAIR: ... just let us know.

Ms SNELL: ... because we have not done anything illegal.

Mr CHAIR: No, I am sure you ...

Ms SNELL: We just share the resources. That is beneficial for the residents.

Mr CHAIR: That is good. I just wanted to reiterate for your comfort, basically.

If a VAD service was introduced—let us say we write the report that broadly says there should be a law. Let us say, hypothetically, the government agrees and then a law somehow gets passed, there would still be 18 months before anything happened because there is an implementation period that is pretty standard everywhere across the country.

The earliest that VAD might happen in reality for somebody who is terminally ill in the Northern Territory is probably a couple of years away. In that time, there is time to figure out how it would work, training, communication—all of that sort of stuff. What would you guys, as ARRCS, like to see provided to help if there was VAD in the Northern Territory?

Ms SNELL: Training in VAD because often there will be retaliation (inaudible). Training in doing it properly, doing it legally, because in nursing you are always scared of losing your registration.

Mr CHAIR: Of course, yes.

Ms SNELL: I think if they want to pass it, nurses need to be more protected.

Mr CHAIR: In that regard, the standard in most places involves somebody who is a fellow—a doctor in their own right who is able to practise independently—having oversight, working in partnership with a nursing team or an allied healthcare team. Is that the kind of model that you would envisage would give nurses that protection as well?

Ms SNELL: No. People get sued. Nurses get sued. As a nurse, you stand alone; that is the reality. No doctor, nobody, is going to stand up for you because it is your registration, and you have got the right to say yes or no. So you cannot say because I was part of a team I just did what the doctor was saying. Protection for the nurses in that sense because there are a lot of stories of nurses being sued.

The problem in remote is the perception that it is a white man's medication, we have come to kill people. So, they will stand up against that nurse, and trust me they can. We are living amongst them; we are in the same community, so we need to feel protected when we walk out of here where they do not say there is that nurse that killed my uncle or my auntie.

Mr CHAIR: In that regard, we talked through a little bit the model that works here. The suggestion is that there would, in order to give people confidence in the healthcare system, as much as possible they would like for the VAD service, if one exists, to be independent of that, so that you do not blur the lines between things. At the same time, we have heard from the healthcare department and others that we know in the Northern Territory people have to wear multiple hats a lot of the time. We simply do not have enough healthcare service to be able to do everything we would like to do the way we would like to do it.

If you had a legal VAD situation and somebody wanted it, would the ideal be for you that somebody came from outside to help with the VAD administration?

Ms SNELL: That would be ideal because if you as a local—Lavenia, if you do it you will be the (inaudible). That is the reality ...

Mr KERLE: So it would have to be someone else.

Mr CHAIR: So in terms of oversight then, all the VAD laws across the country tend to have a VAD review board, some sort of overarching governance that looks after this, looks at the cases when there are any curly questions, they go to the board and they answer them.

We know there are about 1,400 doctors in the Northern Territory. We know that some of them may want to be involved with this, some of them may not, and that is before we even start talking about nurses and everyone else.

If it was the kind of model where doctors and nurses or healthcare practitioners could opt in or out to be involved with VAD services, would that work in terms of creating enough separation, do you think?

Ms SNELL: It may or it may not. There are a lot of blurred lines in a place like Tennant Creek.

Mr CHAIR: Okay, tell us about those blurred lines.

Ms SNELL: A blurred line is that people just really do not believe in dying here. They do not believe in talking about death. We are not able to get people's wishes. We (inaudible) because it is a difficult subject.

Mr CHAIR: Have you completely managed to not do personal plans or care directives?

Ms SNELL: We still try, but it is really difficult and you have got to tread carefully because the moment you overstep (inaudible) they shut down. It is just not something that is talked about. I just do not know how VAD would come into a remote setting like this where people do not even like to talk about dying.

Mr CHAIR: We have certainly found that everybody has been very generous with us in sharing wherever we have gone, but then we also know that, generally speaking, the overarching feeling has sort of been, 'Not for me, but don't mind if other people make their own choice'. We keep emphasising choice, choice, choice. We recently heard, for example, from somebody who works in interpreter services as a liaison officer who suggested that person would not feel comfortable even interpreting these things.

Ms SNELL: They will not. They do not talk about it.

Mr CHAIR: Do you guys work with interpreters much here?

Ms SNELL: (inaudible) interpreters, but even the interpreters they interpret how they want. You never know whether they are (inaudible) because there are certain words in their language that they do not talk about. They do not use those certain words.

Ms BOROTU: I just wanted to know are you also going to, or have you interviewed people in the community to get their opinions or have you only sort of done facilities ...

Mr CHAIR: No, it is a mix of everything. It is time limited is the bottom line. We received this referral to do this inquiry on 14 May, and then we basically spent all of August going out to as many places as we can. Sometimes it has meant sitting out in the red dirt with TOs and locals. Sometimes it has meant being in a council chamber. Sometimes it is in something like this ARRCS facility. It has been very much based on people's willingness, availability and whatever Georgia, Katie and Caroline—the DLA team—have been able to put together for us. We have tried our very best to talk to as many people who want to talk us, but we must be honest in saying that; it is not that we can cover the entire Northern Territory.

We are also not running a referendum on VAD. We are not out here to determine 51% of people think this or that. We are trying to get opinions from the bush as best we can from a representative spread of places.

Only a few places have said that they did not want to talk about this and mostly it was because of sorry business and bad timing. They said to us that now is not a good time to them about this. Some of those communities have come to us afterwards, to Darwin, to talk to us as well. We have tried to cover areas around Tennant, areas around Alice and areas around the Roper Gulf, getting out and about as much as we possibly can.

We have been lucky to have very good translators and interpreters and, as a result, have pretty good, respectful conversations. We have heard some surprising things, like in some places people telling us they have known of people who are ill, have received pain relief and ultimately passed away. They know these kinds of things have happened in the past, without anyone impugning anyone. We know that there is strong opposition amongst Indigenous groups, a lot of them, to the idea of having a lethal oral substance or injection to end their life. What we do hear a lot of consistently, across all levels, is this idea that people would like to finish up well. For some people that means on country earlier than they are getting the chance to. For somebody else in an urban setting it might mean finishing up at home rather than in a hospital.

We would like to be able to talk about as much of this as we can within our report, but it very much depends on what information we get.

Ms SNELL: Have you contacted Anyinginyi and Julalikari?

Mr YOUNG: Tomorrow we are meeting ...

Mr CHAIR: Yes.

Ms SNELL: That should be interesting because they are totally Indigenous.

Mr CHAIR: Wherever we have been, as I said, we are very lucky. We have not turned up anywhere and the room is empty or we turned up and people say, 'No, I do not want to talk about this', and they walk out and leave. Every session we have had, luckily, we have been able to have a good conversation. We learned something; hopefully we were able to answer a few questions as well. Every facility is different. For example,

the ARRCs facility, the Old Timers facility we were in, in Alice, was, I would say, a different conversation to this in some ways as well. It depends.

Mrs CARLSON: They have got independent living there.

Mr CHAIR: We know there is a diversity of opinions.

Going back again to if there might be a law. If there was a VAD law, would it offend you or upset you, if that law existed for other people to use, even if you do not use it?

Ms SNELL: I think it is a good choice for people. Like I said, when I am at that stage I would like someone to do that for me. I would not do that, but if someone feels comfortable to do that because nobody wants to suffer.

Mr CHAIR: No. I think I am in the same camp as you.

Ms SNELL: If someone can just do it for me, I will be grateful, if they can live with that. But I personally cannot do it (inaudible). I am very vocal about not suffering. My kids know as well I do not want any resuscitation; I do not want anything. Let me go. I think for that reason it would be good for to have a law like that because it will tell people that actually feel strongly about it that they can do it to me.

Mr KERLE: Following up on palliative care and about your patients, do you have many people—we have heard some testimony about people who get to a point where the treatment is not working, they are in a lot of pain and they choose to withdraw from treatment knowing that it will bring on the end. Does that happen much here?

Ms SNELL: I know in Western Australia it happens a lot. But I think here people hold on to life until it becomes ...

Mr KERLE: Until the very end, yes.

Ms SNELL: Some of them have no quality of life, but they still hold on.

Mr KERLE: With the pain management—I am just trying to think how to ask this. How does the pain management work in those scenarios?

Ms PENEZ: The comfort?

Mr KERLE: Yes, comfort. Their condition is progressing. How is the pain management dealt with there? Do you guys manage that or do you have like a ...

Ms SNELL: We manage it. It also depends on their choice. As you know, the standards are all about rights and choices. If they choose to have comfort care, then we do it. But end-of-life management is really right at the end. For some reason, there is just (inaudible), which is sad because everyone who comes into care is palliative (inaudible) in my mind. That is a definition of palliative care. They are not end-of-life, but they are palliative because of all the probabilities (inaudible). To get them to understand it is another thing.

Mr CHAIR: What sort of timeframe—I appreciate it is very hard to give a prognosis on timeframes for anyone. When you are saying that in your mind everyone who pretty much comes here is palliative, what sort of timeframes are we talking about then—months to live?

Ms SNELL: Months. It could be maybe years because they prolong. They pump them with medications. People tend to prolong life, even though we all know that it is actually not working. I personally feel that if you have got comorbidities, just to be comfortable. Why are we pumping you with cardio meds if you are not going to monitor your cardio status, if we are not going to do anything about it? Why are you pumping them with this? There has got to be a rationale why we are giving you the things, but people want it and that is their choice for them. They want the medications. Whether there is a rationale or not they do not care, but the doctor must prescribe something.

Mr CHAIR: It is very hard to generalise, of course, in this situation, but is it doctors with a duty of care that are leaning towards trying everything? Or is it patients saying, 'Give me anything you have got?'

Ms SNELL: It is patients because even the doctors in the NT, because of the culture, they are very careful. If you were a doctor saying, 'You know what? I do not think you need this medication', people can turn around, so they generally will give them what they want.

Mr KERLE: With people who are approaching end of life—I am asking this question because it relates to one of our recommendations—like, time to end of life. You just said that people hold on, like how hard is it to estimate how long someone has? Is it really a futile effort? How accurate is it when doctors estimate how long someone is likely to live, if it is more than a month?

Ms SNELL: It is not very accurate in the sense that, to me—and this is me again—if you are finding that your organs are shutting down, you are becoming end of life, I would say, 'Stop the medications', and then just make comfortable. Organs are shutting down, you are nearing the end of life, but you are still getting medication, so, in a sense, you are actually prolonging and prolonging, whereas it could be shorter. But, like I said, people do not talk about dying here, so they do not want to hear, 'You are dying, in any case, so why are we giving you X, Y, Z?'

Mr CHAIR: Irene, can you give us some specificity about that? When you are talking medications, are you talking about cardiac medications or dialysis?

Ms SNELL: Especially in renal because, as you know, renal disease is really prevalent in the Indigenous community. You will find people having dialysis up until the end, whereas in Western Australia they will say, 'You know what? The dialysis is not working anymore. We will withdraw you.' (inaudible) But here people will insist on (inaudible). We had one that had dialysis up until a week before she died because the family wanted it done.

Mr CHAIR: What about self-dialysis? Is that something that just does not happen here?

Ms SNELL: No, I think because of the facilities. If they self-dialyse, the electricity, all those things, the houses are not set up for that. Facilities like ours are not set up to do that.

It is a good thing. Self-dialysis is a good thing because—I do not know if you have been to Nhulunbuy. Nhulunbuy has got dialysis beds.

Mr CHAIR: Yes.

Ms SNELL: I think that is a really good set-up. It is something that I would like.

Mr CHAIR: Yes, we very much wanted to go out there, but the timing did not work out. Oly goes out there quite regularly for various other work things. We have a working understanding of their palliative set-up.

Ms SNELL: They have got a beautiful set-up.

Mr CHAIR: Do you want to tell us a little about it? Because you have seen it in person, I presume.

Ms SNELL: Yes. They have got the dialysis beds and a proper palliative section, which to me is the most beautiful thing to do. So, if someone is end of life, you can transfer them. It is part of the facility. That is something that I am advocating for at our new facility.

There is plenty of room there. Families can come and go; there are no restrictions. It leads to outdoors where they can actually enjoy themselves, get some fresh air and everything. Even if you are dying, why can we not push your bed outside and get some sunlight—things like that. That is what they do in the (inaudible) there.

Mr CHAIR: A number of people have suggested to us that model works very well. Is it also because it is a sort of neutral space? It is not quite a hospital ...

Ms SNELL: Yes, it is a neutral space and it will allow families to do whatever they want. If they want to do a smoking ceremony, if they want to (inaudible), they are allowed. If they are in a set-up where it is (inaudible). Bush meds—medications they have grown up with (inaudible) are prescribed to make sure (inaudible). I think that is strong because they stay cultural, but because of the government legislation that says you cannot prescribe unless you know what is in them, in (inaudible).

Smoking ceremonies, now we have got to wait by the fire alarm. We cannot do it where they want to because we have got to organise for Chubb to come from Alice Springs to come to isolate it, whereas if they were separate it would be easier to do that. We do not have to worry about all those things if they want to do the smoking ceremony; whatever makes them happy.

Mr CHAIR: You have a pretty good understanding of various other aspects of law, which is very helpful here for us. Are there other areas you can think of where things get in the way of providing that, whether it is palliative care or end-stage care? I had not thought about occupational health and safety and smoke alarms until this point.

Ms SNELL: Yes, because I have had lots of calls.

Mr KERLE: If you pay the bills, you know about it.

Ms SNELL: Because people forget and they bill us when the smoke alarm goes off. They are a couple of thousand dollars; they are not cheap.

Mr CHAIR: Are there any other areas of law or any other intersections with areas that end up compromising or intersecting with the care that you provide?

Ms SNELL: I just think it is also legislation like mandated vaccinations and all those things that come in the way of people actually wanting to just be with a dying person. I know we have lifted the COVID vaccines now, but now they have got the flu one, so unless you are vaccinated against the flu, you cannot come in and see the dying person. I think those are things that the government really needs to have a look at because who cares when you are dying.

Mr CHAIR: In that context we are coming back, I guess, in a roundabout way to the idea of withdrawing from care or electing to not have a treatment. As you pointed out before, concerns for nurses or medical practitioners in terms of their liability in providing care and withdrawing from care—would you care to make any further statement about that? We are trying to ascertain how we can help people make a choice if they want to withdraw from care. Are they adequately able to do that at this stage?

Ms SNELL: No, not at this stage. It is really just the stigma of dying here. It is a big stigma and I do not know how we would overcome that.

Mr CHAIR: I realise it is just Irene and me having a conversation at this point. All the other nurses—we have a room full of nurses and carers—is liability something that you worry about in terms of how you provide care here?

Ms BOROTU: Yes, definitely. Especially when you are living in the community, you actually bump into a lot of people outside. I have done here and I have also done communities, so I know some family members and stuff like that. It is a little bit more personal, I guess, than when you are living in a city. So, yes, they might take it more personally if you do something to a family member and so ...

Mr CHAIR: Gotcha.

Ms BOROTU: I think it is a lot different than when you are working in the city, yes.

Mr CHAIR: It is not just the risk of being sued, it is the 'I live in this community and see these people all the time' kind of part of it as well.

Ms BOROTU: You just want to do the best for their family member and you do not want to be perceived like you are doing something bad to them, because you are not here to do that; you are just here to help.

I am definitely for it. I could see it possibly working outside the facility, where somebody like a specialist comes in and it all gets sorted. I do not know how—I have not seen it in certain other facilities—how that would happen here. Being here for only a short period, I am not sure how it would work based on my experience.

Mr CHAIR: This report recommends that voluntary assisted dying should be able to happen in these kind of facilities, or it should not be a preclusion that you cannot have it in a nursing home et cetera. It does not mean you have to have it. In the early days in Victoria, as you pointed out before, there were prohibitions against even being able to initiate the conversation.

One of the things that comes up a lot in our conversations is 'where' matters quite a lot. Where in terms of a hospital, where in terms of an aged-care facility and where in terms of out on homelands. If there was a VAD law, where do you guys think would be the appropriate place for people to be able to access that service? Where might be inappropriate, in your opinion?

Ms SNELL: I think it should be in a (inaudible) facility.

Mr CHAIR: Does that include a hospital as well?

Ms SNELL: Yes. It would be appropriate if it was in the community. I just do not know how they would do it in this community. That is something that (inaudible) because I think we need to have a step down in between facility and hospital and in between that type of palliation and doing all those things.

Mr CHAIR: That step down looks like Nhulunbuy; is that what you are getting at? That step down in between those sort of things is that the kind of Nhulunbuy-like set-up that you are talking about?

Ms SNELL: Yes, although Nhulunbuy is affiliated with a facility, but I think there is a room to do that as a step up in between.

Mr CHAIR: Yes, we understand what you are saying.

Ms BOROTU: In other facilities as well, I feel like if it is done in a hospital in some other Aboriginal facilities I have worked in, they already have a perception—the residents—that 'I do not want to go to hospital' because (inaudible) like she says they associate that with death. If they are already thinking that, nothing is already happening there, I can only imagine that nobody would want to transfer to hospital when they are really unwell. That is what they wanted, but now they have got this perception, they do not want to do that anymore, so it kind of hinders their care. I think maybe a place that is made just for that; you would have to build it. That is kind of what I would see because I would see problems arising definitely.

Mr KERLE: We heard this morning in Alice Springs that they are doing a publicity program around trying to talk about the hospital as a place of healing because they are running into people being really hesitant going to hospital because they are scared that they will die there and they are scared they might be killed there.

Ms BOROTU: The other thing, that is why I asked you have you been interviewing people in the community because I wanted to know are you getting the opinions from people that are actually going to be making these decisions, because they are the ones making the decision very soon rather than us, so that we are not actually speaking on their behalf when really I am very different to them and their cultures and their beliefs. I would rather know that this is what they want and what their opinions are, rather than you are just going around facilities and asking us as staff members because it is really based on their decisions. That is what I would want to know as well to be confident in a decision like that.

Mr CHAIR: We are speaking to stakeholders at whatever levels we can which, as I say, is a mixed bag. It is very much based on who is willing and available to talk to us and the fact that we are doing this within a time-limited period. We are sort of caught between a rock and a hard place where some people would like us to do this for much longer to be able to get much more data and then there are other people who are just like, 'Get on with it; you are dragging this out.' All we can do at the moment is—we are a committee of parliament and we have been directed to do this work within a time-limited period, so we are trying to get on the ground as much as we can. We are trying to speak to hospital settings, traditional owners, local council authorities—basically, whoever will talk to us within the time that we have.

The other thing to add in that regard is that this is not the only piece of work. This is the latest piece of work looking at all of this. This piece of work, which we have been asked to look at, its survey suggests, for whatever it is worth, that there was 75%-plus support in the Northern Territory for some sort of voluntary assisted dying law. The sense was that we could find out more about how people out bush and Indigenous people feel if we it a little bit more time to look into that. That has been the real focus of our time, if you like. We freely acknowledge that it is not that we have been able to get to every community in the Territory or to speak to every single person, but in some places it has been large groups with a translator and we get a sense; in other places, it has been very one-on-one conversations. We are not just speaking to people who run ARRCS facilities.

Mrs CARLSON: The sense in community is that they would never use it. It is something that—they have got their cultural beliefs. Then a lot of them also have a very strong religious belief as well. Obviously, this

facility is part of that type of structure as well. It is something that they are probably not going to use. However, what we have tried to uncover from them is whether they will be okay if someone else wanted to use it. Would that harm them? That is where our conversations have been with those Indigenous communities. It will affect them because it affects them with that stigma of coming to hospital, coming for care and going away from homeland to these places that potentially would have those facilities or some kind of relationship with voluntary assisted dying. We have had to have some real different conversations and interpreting that in language so that they understand the difference.

Ms SNELL: Also, what happens in Indigenous communities is that you may, for instance, my mother-in-law father is on the way. I may decide that, yes, I could do that. Then my brother, my sister, my cousin and everybody decide against that. That is the feeling in the community as well because today one or two may decide, yes, they want to go with it and then tomorrow another group comes and says, no, you have no right to decide and then everything falls apart. It is very difficult because it is not a decision that they can make and stick to. You will get everything ready and get the team here to come and do it, and then they decide, 'No, we are not doing it'.

Mr CHAIR: It is important to say you can opt out at any stage. Even if something like that did happen, which I am sure it would in reality, at any stage of this process—at any stage—you could withdraw. You could go through all these hurdles and then, at the end of the day, decide, 'No, not for me'.

In regard to the complexity of cultural decision-making, we hear that over and again. We understand kinship relationships make it complex for people to make a group decision regarding healthcare. The standard elsewhere around the country—and I imagine the legal standard in this place—would still come down to the patient themselves must want for this to happen. Beyond that, who else might want to be consulted or should be consulted, we can certainly recommend in our report that if somebody hypothetically in the future out bush wanted access to something like this, it would be wise to make sure that their kinship group ...

Ms SNELL: Definitely, because that person cannot make their own decisions. It does not matter amongst ...

Mrs CARLSON: In saying that, what we also have to define in this report is obviously the consent part. If it still comes down to the individual, they may not then be a candidate, unfortunately, if they cannot meet all the criteria.

Ms SNELL: The patient from the community, they may decide that they want this and they are competent enough to make the decision, but the pressure from the community and the families, they just—you know, it is not worth it and they (inaudible).

Mr CHAIR: It does not just happen in Indigenous community settings. We have heard other instances of a person wants this but they know that their kids or their family does not want it, so they say to the healthcare provider, 'Look, I want this. Can you please not tell them because this is what I want but they are going to kick up a fuss.' That makes it very challenging. But to provide somebody equity and access and opportunity, you have to allow a provision for that at least.

We know that we are probably talking about less than 20 people a year in the Northern Territory that might use this, if you are to use the statistics from other places and extrapolate. About 500 or less people a year use this in Victoria. In Queensland, it is slightly getting higher but it is still under 1,000 people a year. We want to make sure that it is available to anybody who wants it, but we also know that we probably cannot build a whole new part of the healthcare system to facilitate for a very small number of people, particularly if there are pressures elsewhere.

This is a question I want to ask you all in that regard. This report, with good intention, suggests that to give everyone confidence in everything we should have a standalone service. We are increasingly finding it hard to picture what that standalone service might look like with limited money and with limited healthcare workers and providers and all the complexities that we have discussed. Can you envisage—we are just spitballing here, so we are not holding you to anything—as healthcare providers, facility managers how do you see a service for this working? What is like a dream scenario of how this would work?

Ms SNELL: The dream scenario would be we had a standalone and fully staffed, and people are actually allowed to make those choices. That would be—and I cannot see it happening. I come from South Africa and we have actually had VAD. I worked in hospice where we had VAD. There was like a sunflower room, you know, beautiful bright and everything, and you opt to do that. But I cannot see it happening here. I just cannot see it.

Mr KERLE: That might have to be something that happens down the track once it is very mature over time and there are more resources, I think.

Ms SNELL: I just do not know. How do you overcome the stigma?

Mr KERLE: The stigma; sorry. I am thinking more like the standalone VAD service in a place like this if you have got cultural considerations.

Ms SNELL: Yes, I cannot see it happening.

Mr CHAIR: Did you want to add something?

Ms FORSYTH: Yes. How much education is spent, like I know you are aiming this at the Northern Territory because Victoria has got it. You are aiming this to me, as our First Nations peoples; they are not the only people who live here or even in the Northern Territory or in Darwin or Alice Springs. You look all over Australia at what different cultures want this. It should be a choice. As I say, it is a choice and the education needs to be out there. Is it more so—and Irene was saying about the nurses getting sued if something. In Victoria we were not allowed to be a part of it, so maybe you need to keep that. If they said that to us, we would go straight to the clinical—I would go to Irene and go, ‘Hey’, and she would be like, ‘Hey, leave it with me’. First call to the doctor, doctor comes and sees the patient, end of story. That is between them. [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Mr CHAIR: That bit can be redacted.

Ms FORSYTH: You know what I am saying. I told you what is happening in Victoria and what I was a part of in Victoria.

I think the education needs to get out. We had a lot of education on it, a lot of things on walls, a lot of things where family members came in. That is different here with First Nations people, and I get that it is everywhere. But there are some really lovely First Nations people out there who want it.

Mr CHAIR: Yes, we have found them.

Ms FORSYTH: If you go into the communities, of course they are not going to want it. I worked in Western Australia for six months. You mentioned the word ‘morphine’ and gone. Like, we had two residents who passed away in the most cruellest deaths I have ever seen, but I had to respect what they wanted. We had to bring social workers in, we had to bring people in from the hospital, just to come and even educate them on ‘why can’t we give them some pain relief’, you know.

Mr CHAIR: Where did that story land? What happened in that situation? Can you tell us any more of it?

Ms SNELL: They just died. They were vomiting up blood. It was horrendous, even for us. Like, we even had to have (inaudible) drugs. It was horrendous that they were given nothing—no midazolam, nothing. They just (inaudible). The head honcho of the family just said, ‘Nup, nup, nup’, and let it go. So, they bled out, basically, but quickly. It was not a long death, but we all managed to see it.

I think we need to get education out there and we need to actually have people driving notifications in doctors. It needs to be spoken more about by the doctor, more clinics more. Just from what I am taking from this.

Mr CHAIR: It is super helpful what you were saying, and we will certainly I think try and put that into our report.

Just to give you a small bit of comfort, even if our law gets passed, whenever that might be, there would still be an 18-month period most likely before implementation of anything. That 18-month period would be the

time when you would expect that there would be robust education and implementation plans, whoever the key stakeholders were—the review boards, whatever—that they would determine all that stuff.

We are not, honestly, here to fix the entire healthcare system, but we can reflect on the things that intersect with VAD to help people who might think about passing a VAD law to understand that if you pass this, it is not just about this; it is also about palliative and aged care and cultural things, interpreters and all of this stuff is part of it.

Just to your point about it is not just Indigenous people who we should be looking at, you are absolutely right. Our specific ask was to go out to remote communities. We were asked to do five things. The first one was to write a consultation paper, which we did. That is available and we will leave a copy with you guys as well. The second was to go out to remote communities specifically to ask about this, hence the specific focus on thinking about Indigenous health a lot. The fourth and fifth things were to look at other VAD models around the country and figure out how it might work here specifically in the Northern Territory. Then if you reckon there is majority support for this, provide drafting instructions for a Bill. We are trying to multitask all those tasks so that we can try and get everything done in the right timeframe.

But it is very clear to us how important communication is, interpreters are and implementation plans are. We know that the whole thing could be an absolute shemozzle if people did not have better communication. Out here, for example, the conversation we are having with you guys, lots of questions, the same with everywhere we go. A lot of the time we hear, ‘We have not heard a lot about this yet. I came to learn as much as to give my opinion.’

Our remit stops once we submit the report. Then, truthfully, it becomes up to the government to decide what communication they want to do or whether they even want to go forward with it. But assuming they do, I am sure that they will have an eye to making sure that things are communicated over a lengthy period properly to people across the Territory. That includes in the cities, of course, not just out bush.

I am mindful that we have got about ...

Ms SNELL: Hopefully, they will manage it better than with COVID, because the intake was so low and that was just because communication ...

Mr CHAIR: Yes, it was not strong.

Mr KERLE: A quick question before we finish up, because we were just talking about administering pain relief and you mentioned morphine. We have a mix of ENs and RNs here. At what level are you allowed to administer according to a prescription? Is it only an RN or are ENs allowed to do it?

Ms FORSYTH: Both ...

[Multiple people speaking.]

Ms SNELL: AHPRA says the EN can do it with an RN.

Mr KERLE: If an RN is supervising, then an EN can do it; okay. You really need an RN, that is the minimum?

Ms BOROTU: You need 24 hours now ...

[Multiple people speaking.]

Mr KERLE: What is 24 hours?

Ms BOROTU: In the morning, pm and night there has to be one RN on that list.

Mr KERLE: At all times.

Ms BOROTU: Yes.

Mr CHAIR: This is a very well serviced, regulated, functioning facility. We can see that. Some places obviously do not have that RN, which makes palliation very difficult, but it is useful to know even if there are limitations in your system in that regard.

Ms SNELL: ARRCs is pushing for RNs (inaudible).

Mr CHAIR: Okay. Do you have nurse practitioners as well in your roster?

Ms SNELL: No. We would like to, but nobody wants to come and work in NT.

Mr CHAIR: We are mindful of that. Good luck with all the bribery you are doing.

Ms SNELL: Nurse practitioners would be really fantastic.

Mr CHAIR: How would you see nurse practitioners fitting into this, hypothetically, if you could get them here?

[Multiple people speaking.]

Ms SNELL: They would make our life easier because there are lots of things that actually do not require a doctor. It just needs a step higher than a nurse.

Mr CHAIR: Could you just, for the record, spell out maybe two or three of them?

Ms SNELL: Antibiotics, UTI. I can tell you I know the sensitivities, I know what (inaudible), but I cannot prescribe. Why do you need to go to a doctor to have them prescribed?

Mr CHAIR: We understand. The bottom line is in other places there is a suggestion that lots more nurse practitioners would be very helpful. In the Northern Territory we know that we do not have enough allied healthcare workers and nurses, let alone nurse practitioners. Even though per capita we have more doctors than anywhere else in the country, we still do not have enough to actually deal with our burden of disease and geography and demography. There are capacity limitations for everything.

This is a new thing. We know that it will require resources, but we want to make sure if it does come through, then at least it has the best possible chance of succeeding or not being a disaster from the beginning—of lack of communication, as you put it.

Ms SNELL: Just out of interest, why NT, why do they think that there is a need for VAD in the NT?

Mr CHAIR: The quick history again was in 1995 we were the first jurisdiction that had a voluntary euthanasia law pass. That was then overturned the year after by the federal government. Then 20 years later the federal government decided now that territories could have a law. In the meantime, every state and territory in Australia has had a VAD law passed. Now the Northern Territory, which was first, is last.

There is still a popular push from long-term Territorians and whatever data has been collected to suggest that there is a majority of Territorians who would like some sort of legislative provision for voluntary assisted dying. This report got commissioned last year, and we have been asked to look into this report by the current government. That is where things are at in terms of the story of it. It has not come out of nowhere; it has actually just been an ongoing story for 30 years.

Ms BOROTU: When it did pass back in the day, was there any services that did happen during that time?

Mr CHAIR: Yes, there were four people who over a nine-month period—it was called the *Rights of the Terminally Ill Act*. It was very different than what these models are in terms of checks and balances. It was more essentially providing protections for clinicians from being able to administer a lethal substance to be able to allow someone to pass on. There was a different set of hurdles and protocols there, but essentially it was signed off by a doctor, signed off by a second doctor, a psychiatrist needed to be involved at that stage as well, and there was only one medical provider who led the charge, essentially, and helped four patients with a voluntary assisted death.

Thereafter the federal government—it was not actually the federal government; it was an individual within the federal government in 1996 who passed a private member's Bill, a gentleman called Kevin Andrews—made the law that territories should not be allowed to make laws about euthanasia. Not specifically that euthanasia was outlawed, it was just the territories did not have the capacity to do that.

Four people did access it and we, in fact, spoke to the widow of one of those people, the first person to access it. There is a number of people who just want us to just scribble out '1995' and put '2025' in and just resuscitate the old Bill. That is probably not realistic in the modern age. We probably need to look at what

this report and the rest of the country is doing now, which is a little bit more. There are more boxes to tick, as was pointed out before.

Mrs CARLSON: It probably was not communicated—because I was around; I was a teenager when that happened. The communication was actually very limited about it. There was a lot of scaremongering obviously, which is why then the doctor who did assist tried to come up with a solution that tried to fit that, to cover all of that. But I think we have come—after 30 years, some of that conversation now is getting better and better, hence why we have probably had a very positive reception in some of the communities and a lot different to 30 years ago.

Mr CHAIR: There were fears, 30 years ago, that the introduction of that law would lead to a drop in people, Aboriginal people particularly, accessing healthcare services. There was Health department data and then a Senate inquiry afterwards that found that did not actually end up being the case. But it was around for such a small window that it is hard to say what really would have happened because, really in practice, it was only available for about nine months and then it was nixed and then was not available for a very long time.

Ms SNELL: There are other ways than medications, so it was not (inaudible).

Mr CHAIR: Yes, that is true.

There are lots of trust and communication issues across this entire thing. Communication and education is a huge part of it, we agree. We can only inform in the report that we really believe that the communication and education part should be really well thought out before anything happens, but beyond that it comes down to the government of the day.

As you say from your experience in Victoria, it was not perfect to start with. It took a while for them to iron out some of the kinks in that situation. Now every state and territory has deviated ever so slightly. In ACT for example, there is no 12-month prognosis limitation. In every other state and territory, essentially, the medicos have to sign off to say that 12 months or six months, depending on the condition—but generally 12 months—you are dying within 12 months, I am signing off on that. In the ACT they have decided to dispense with that because they think that is arbitrary. All the experts who have looked at it have suggested that maybe this is not a reasonable requirement. That is another thing that we will have to think about.

Ms SNELL: Who knows? You can never say.

Mr CHAIR: That is right. Who knows is essentially the argument in simple terms; you are right. But we will have a think about all of those things.

Before we wrap up completely and have a little look around your facility, is there anything else any of you want to raise; anything that we did not cover or any other questions you have? We are still around; while we are wandering around we are happy to answer questions. Anything else anyone can think of?

Ms SNELL: I just think the name is so wrong.

[Multiple people speaking.]

Mr CHAIR: What would you have it be? Why is it problematic?

Ms SNELL: Because the name says you are helping me to die; you are killing me.

Mr CHAIR: What would you rather it said?

Ms SNELL: Just a softer name that has got something like ‘comfort’ or ‘transition into another life’—something like that. Because the name is ...

Mrs CARLSON: Harsh.

Ms SNELL: When you look at that name, it is like, ‘These people are coming to kill us’.

Mrs CARLSON: Especially when you say the letters, V-A-D.

Mr CHAIR: Language is very important and words are very important.

Ms SNELL: English is not my first language, so when I look at 'VAD' ...

Mr CHAIR: I do not like VAD either. Personally, I also remember when it was euthanasia, which translates to a good death in Greek. That made more sense to me, but VAD is what it is called now in the country, basically. I agree.

Ms SNELL: You need to make it sound really good, helping people to really get comfortable to die, normally.

Mr CHAIR: The original Act in 1995 was called the *Rights of the Terminally Ill Act*. That seems to be something that people who were around from back then still have a strong attachment to. That is another thing that we will hopefully mentioned in our report to say that giving terminally ill people rights is something that people feel strongly about. Maybe we could be talking the modern version of the *Rights of the Terminally Ill Act*, rather than voluntary assisted dying legislation.

All we can do really is write a report and make suggestions. As Dheran pointed out, we are from different political parties, but we are trying to work together on this as a team to just make the best decisions we can for Territorians. Then we leave it in the hands of the government to decide what the best way forward is. We really will try our best to reflect as much as what we hear from you guys, as well as everyone else we have spoken about, in our report.

Thank you so much for your time today. We really appreciate all of the time and hospitality and all the questions.

Just as a final thought, if you have anything further you want to add, we are still accepting written submissions, even if it is one line on a scrap of paper. Until the end of this week you can send an email to LA.VAD which is on the papers we have got here. We also have our phone hotline. If there is anything you wanted to say confidentially, or whatever it might be, you can always call as well and say, 'I forgot to say this', whatever it might be. Please make a contribution in that way too if you feel like you want to. We will certainly endeavour to try and let you know how things are going as things go forward.

Ms SNELL: I will watch this space because this is going to be interesting in NT. I would like to see if it will work. It is interesting. I hope I will still be alive.

Mr CHAIR: Touch wood; you look pretty fit and fighting right now.

Ms SNELL: It will be interesting and it would be good to be part of a project like this. I think it is good for some people. It is good that everybody gets a right to decide.

Mrs CARLSON: Yes.

Mr CHAIR: Ultimately we hear that a lot, choice; people are okay with people having a choice. But we want to make sure beyond just saying, 'We are okay with people having a choice', we have had a bit of a think about how will this actually work to make sure that it can still work; we do not just give people a choice that does not actually give them a choice and it is just a choice on paper.

We will try our best. We certainly benefit from all the wisdom of everything you guys are telling us. Thank you for sharing with us today; we really appreciate it.

Let us wrap ...

[Recording ended.]

The committee concluded.
