

The committee convened at 11.07 am.

INQUIRY INTO VOLUNTARY ASSISTED DYING
Maningrida Progress Association
Nja-marleya Cultural Leaders and Justice Group
West Arnhem Regional Council
Mala'la Health Service
Bawinanga Homelands Aboriginal Corporation
Homelands School Company
Dukurrdji Development Corporation

Mr CHAIR: Thank you so much for coming down today. We genuinely appreciate that you have come a long way to talk to us. We are sorry that we were very tardy in being here. It is probably a first that we have come in here and everyone is lined up ready for us already. We really do ...

Unidentified speaker: We have lost one while we were waiting. He is still coming.

Mr CHAIR: Good. Hopefully they will make it in as well. Before I say anything else, on behalf of all the committee, we want to respectfully acknowledge all the traditional owners of this country as well the country that you come from, and pay our respect to elders past, present and emerging.

Thank you for joining the committee here today. We appreciate you taking the time to travel. My name is Tanzil Rahman; I am the Chair of the Legal and Constitutional Affairs Committee. I will let my colleagues introduce themselves.

Mr KERLE: My name is Matthew Kerle. I am the Member for Blain. I represent Woodroffe, Moulden and Bellamack in Palmerston. I am the Deputy Chair of the committee.

Mrs CARLSON: My name is Oly Carlson. I am the Member for Wanguri. I represent the areas of Wanguri, Muirhead and Leanyer, which is side by side to the Casuarina electorate, with Casuarina and Royal Darwin Hospital.

Mr CHAIR: We also have online ...

Mr YOUNG: Good morning. My name is Dheran Young; I am the Member for Daly. I represent the communities of Daly River, Palumpa, Peppimenarti, down to Wadeye and then all the way up to Wagait Beach, Dundee and the Berry Springs rural area. I am also a committee member.

Mr CHAIR: We are here today to talk about voluntary assisted dying—VAD. It is using a prescribed substance to be able to hasten someone's death when they are terminally ill at their request. It is a process that gives an eligible person—not just anyone—the choice to ask for medical help to end their life in a manner and time of their choosing.

We know that talking about VAD can be very difficult for a lot of people. It upsets a lot of people to talk about death and dying. We always say at the beginning, if anyone is feeling upset or wants a break, we have support services available, and we are very happy to take a break at any time if anybody wants to.

We are recording this meeting. We hope to use the transcript of this meeting as part of our evidence that will help us form the report that we have been asked to write about voluntary assisted dying legislation—possibly—for the Northern Territory.

If there is anything that you want kept private in the conversations we have, please tell us and we will then note that and exclude that portion of the proceedings accordingly.

This is also a formal proceeding of the committee and protections of parliamentary privilege apply.

Could we start by getting everybody to introduce their name and the capacity in which you are appearing here today.

Mr NAMANURKI: Shane Namanurki, Chairperson for Maningrida Progress Association.

Mr JONES: David Wuridjal Jones. I am the Chairperson of Nja-marleya Cultural Leaders and Justice Group.

Mr WOODS: Mayor Woods, West Arnhem Regional Council.

Ms MURRAY: Katharine Murray, CEO of West Arnhem Regional Council.

Ms WOOLF: Lesley Woolf. I am the Executive Health Manager from Mala'la Health Service.

Mr CHAIR: Fantastic. Who do we have online? Anybody want to start? Kira? We cannot hear you, you are muted.

Ms BOURKE: Sorry about that. My name is Kira Bourke. I am the CEO at Bawinanga Homelands Aboriginal Corporation in Maningrida.

Mr CHAIR: Who else do we have?

Mr SHARRAH: My name is Nic Sharrah. I am the Chief Executive Officer for Homelands School Company based in Maningrida.

Mr LONGBOTTOM: I am Adam Longbottom, CEO of Dukurrnji Development Corporation at Maningrida.

Mr CHAIR: Fantastic.

Ms RAMADANI: Good morning. Seide Ramadani, CEO for Nja-marleya Cultural Leaders and Justice Group.

Mr CHAIR: I think that is everyone. Is that everyone? It is nice to have a full house. Thank you so much again everybody, for making yourselves available.

I will provide a little context as background for everyone so we all know where we are. Last year, an independent expert advisory panel produced a report about voluntary assisted dying. This committee was asked to look into the findings and recommendations of that report to work out whether or not the Northern Territory should move ahead with voluntary assisted dying legislation in some form.

The terms of reference for this committee were to produce a consultation paper—which we have done; it is available publicly on our website; then to extensively go out bush and try to consult with remote communities to find out what they think about this, which is why we have been out and about; then to look at what specific thing might make voluntary assisted dying work better in the Northern Territory; and finally, if appropriate, to recommend drafting instructions for model legislation.

To be clear, our remit is not to pass or even make a law, it is to write a report back to the parliament. Then the parliament will consider what to do with that report. We hope to report back to the parliament in September.

We know that voluntary assisted dying intersects with a lot of other things. It is useful for us to understand about those things in different places. Probably the first thing that we want to ask about is healthcare services in your community. What are they like at the moment? What has been your experience? What, if anything, could be improved? I am happy to hear from anyone.

Ms WOOLF: Health services in Maningrida are run by Mala'la Health Service. It is an organisation that was established in 1998. It has a good history. Initially, really we only employed doctors, but it has grown considerably and we have an aged-care facility which has 10 residential beds and about 70 community clients, plus NDIS services.

We have a primary health service, which is probably the biggest in the Northern Territory. It runs a 24-hour service. We are fortunate enough to have some urgent care funding. We believe it provides a very good service to the community. We try to be responsive in every way, but it provides a good service to the community.

There is also family and community wellness which provides a lot of support with counselling, psychology services, a cultural women's centre and a men's shed. There is a lot of support provided.

The three distinct areas work closely together. While the aged-care facility does not employ any nursing staff, basically it is across the road, so they get very good medical backup.

In the community there is a greater desire, I guess, from the community to have palliative patients in Maningrida, and let them die on country, which I think is important.

We are in the early stages of planning extensions to aged care, which will include two palliative care beds. At the moment, we do not have any palliative care beds, so basically we send somebody home so that we can accommodate a palliative care patient. There is certainly a desire for people to die on country. We try to endeavour that the end-of-life journey is as good as possible.

I think that is all.

Mr CHAIR: That is comprehensive, thank you. That is a good frame in.

Mrs CARLSON: Lesley, I have one question in regard to the facility and everything you just described. What is the furthest distance someone needs to come from homelands that maybe one of your residents—would come the furthest?

Ms WOOLF: Probably an hour-and-a-half to two hours, depending on the road.

Mr CHAIR: You touched already on ...

Ms WOOLF: Sorry, it is hard to say in mileage because we tend to talk about ...

Mrs CARLSON: Yes, I was about to say mileage.

Ms WOOLF: ... hours because it is dependent on the road.

Mr CHAIR: Aged care and palliative care, as you would appreciate, are things we are interested in as well. Can you tell us how you manage people who are extremely ill, extremely aged or in a palliative setting at the moment?

Ms WOOLF: People have the choice to stay at home or, if they would like to be in aged care we can facilitate that—wherever we can, we do. If people prefer to die at home or be at home, that is fine. The nursing staff from the clinic will go and visit them every day, sometimes twice a day, and provide pain relief, whatever needs to happen.

Because we have staff on duty 24 hours a day there is always somebody available from the clinic should a patient require pain relief or some assistance.

If they move into aged care, we have an area where they can be. We allow the family to all be there if they want to be. We have built what we call a quiet room, but it is a room where family can sit. We make sure they have tea and coffee; they can make that themselves—all that sort of thing. We facilitate pain relief and ensure that is happening and that their journey is as culturally appropriate, but as comfortable as possible.

Mr CHAIR: We have heard consistently across the Territory that a lot of people out bush would like more help and choice to finish up. That is the phrase that we found. A lot of people do not necessarily want VAD for themselves, but they would like more help and choice to finish up.

We are trying to work out how we can provide that. Again, we hear that whilst people would like to finish up on country, sometimes they do not manage to get back in time and that there are frictions in the system. Are you able to advise us at all about whether people have been able to come back in time, whether people get stuck in hospital and what that communication is like?

Ms WOOLF: There have been a couple of situations where people have not got back in time. Basically, it has been a breakdown of the system. We use a different clinical IT system to what the hospital uses and sometimes having access to the appropriate information is not possible. In saying that, we have good relationships with the hospital and try to work as closely as possible. The hospital is conscious that people want to die on country and, wherever possible, tries to facilitate it.

We are constantly in meetings with the hospital trying to improve communications, making sure that things are happening.

The fact that we are getting an additional two palliative care beds will certainly help in terms of that transition.

Some of you guys might have personal experience.

Mr CHAIR: Shane, David, did you want to comment? Remember, if you would not mind, to press the button before you speak.

Mr JONES: It is really hard when a loved one has passed away. In my community, when people die, they do not really come and let us know. They choose to come back home and to let us know to die. So (inaudible) he stayed with us. We are working together.

People in the community worry. They are leaving their old loved one. We know what the background is. We need to know what is happening to my people dying. That is how community—they need to know what the real story is.

Mr CHAIR: Do you find that the communication is not good at the moment?

Mr JONES: No.

Mr CHAIR: It is not good. Okay. Do you mean particularly if somebody is sick in the hospital? Or if they are sick in Maningrida? Where is the communication?

Mr JONES: People are dying here, sick and go back home. So both in the community and mainly in the city, no-one really comes and tell us, the families, to know what the loved one got (inaudible) problem. That is what we need to know.

Mr CHAIR: What about telehealth services? Do they get used much in Maningrida?

Mr WOODS: Yes. We have telehealth regularly, daily mostly. Just to go on from what David and Lesley were saying. It comes down to that communication on both sides regarding the individual. More consistency is needed with the palliative units regarding—for clients to return on country. Once they get to country, this is where they should assist with Mala'la in a way of returning the individual to their homeland so they can die on country, instead of just in Maningrida. That is where that breakdown in communication is regarding moving from where the person gets sick in the community, they go to Darwin, gets informed and then goes to get back home to their actual country. That is the breakdown in communication regarding logistics, not just verbally between the patient and the professionals.

Mr CHAIR: There is a communication issue there. Is there also a language barrier issue there? With interpreters or ...

Mr WOODS: It goes both ways because the client's family is your interpreter already. Then if there is still a breakdown between them and the professionals, that is where your interpreters need to come into play. That is what I am saying about the communication of the logistics.

Mr CHAIR: We have heard a mixed bag when it comes to telehealth. Some people say it will solve a lot more problems. People in other places have said that it does not work very effectively or efficiently, may be not for court processes let alone for health purposes. It is good for us to get a sense of how well it is working for you guys.

Ms WOOLF: We have a telehealth service at aged care and we are in the process of purchasing another telehealth card—a new one for the clinic. We already have one.

We also employ three telehealth doctors. They work offsite. One works from Queensland; one works from Victoria; and one works from Darwin. Two of those are available each day. One of them has been with the organisation for seven years, both onsite and offsite. A lot of people have a very good relationship with her. That makes a difference. She is responsible for aged care, and she will often pick up some palliative care as well.

Then we have an onsite doctor who is permanent. She has been there for seven years. She has a great relationship with the community and also deals with a lot of the telehealth. We have locums. We normally have three doctors on the ground all the time, plus three telehealth doctors. We have extremely good medical services and they all have a fairly long relationship with the organisation at Maningrida. Most of our locums are returning locums. We do not get many new locums. We have a relationship where we just plan for the year ahead. That provides a lot more services as well.

I do not think our telehealth services are perfect, but they are certainly improving with the additional telehealth doctors. At any time a nurse can go out to a person's house and dial the telehealth doctor and have them there to talk to them, FaceTime them or whatever. I think that helps.

A lot of these things are developing. We have been fortunate to receive some funding from NACCHO for a cancer-care nurse. I think that will help in terms of palliative care as well because it is a specialised area.

Mr CHAIR: The circumstances for Maningrida are different than many communities, as you know. You are obviously large and well serviced compared to some other communities.

As you know, we have been tasked to look at voluntary assisted dying specifically. The 2024 report suggests that there is majority support in the Northern Territory for some sort of voluntary assisted dying law to give people choice if they are terminally ill.

We are not running a referendum or a poll, so we are not testing that support; that is not our interest. Our interest is in asking how individual communities feel about it. In some places people have said to us they are not necessarily interested in it for themselves, but they do not mind if other places have it; it does not offend them, for example.

Welcome Charlie as well. Sorry, I should have said hello before.

Can you guys give us a sense of how you feel about voluntary assisted dying laws?

Mr GUNABARRA: Maningrida is a big community; we are probably 4,500 people. Most of them are from homeland, from bush or living in Maningrida. We do not know when people are very sick, their time is coming—we do not know. It is just a matter of a big shock when somebody is losing his life.

We have a lot of nurses on the ground are very good. We go to homeland, take doctors and nurses and even a driver of the helicopter to go out and do all the checkup in the bush. We have about 25 homelands, but most of them all live in community—sort of move back.

I believe back in the bush is more healthy than community. That is why people are getting sick. It is a big shocking thing, what is happening in our community. Most of them do have checkup at the clinic. Most of them do not like to do checkup and we do not know. Most of them are scared to come down to clinic. But it is good that we got doctors and nurses up there working 24/7. It is really good that everything we are dealing with, like will be there for life and death. Who knows? It is a matter of trying to come for these people. Also when they are very sick they—like Lesley was saying, we are fairly cultural family and they need to understand where it is coming from and what their family condition is.

Maningrida is a big community and we can only save lives.

Mr CHAIR: Carry on Charlie.

Mr GUNABARRA: No, no.

Mr CHAIR: I was going to say that in the rest of the country when voluntary assisted dying—VAD—laws have been passed, we know how many people, roughly, have been taking it up. In Victoria, there have been about 450 people a year since they started doing it in 2017 and onwards.

In the Northern Territory we estimate that if there was a law like this, it might only be taken up by 10 to 20 people a year. We know that some of those people might not be out bush, but also if somebody in the bush did want to choose this, we want to make sure we could help them if they want that help.

Do we have people in the community setting at the moment who are supportive of that or might be willing, as health workers, to deliver a VAD service? Is that something that any of you can speak to?

Ms WOOLF: I am not sure that it is something that has been thought about. There are a lot of spiritual thoughts as well. I am not sure that people would necessarily take it up.

A lot of our sick people and the aged care have advance health directives. Certainly, their end-of-life journey is discussed with them but I do not think that voluntary assisted dying is on their radar because it is not something that has been discussed.

Mr CHAIR: With advanced health directives, have you had much resistance to discussing those? Or is it commonplace in Maningrida now that when people are really sick or aged that you are able to help put together APPs and so forth?

Ms WOOLF: The doctor puts it to the patient, but it is their decision. They can say, 'No, I do not want that'. People also know that they can change their mind today. It is not set in concrete. When it is explained to people, as long as they understand what is being said and certainly, as James said, we use family to interpret, they know they can change their mind. They might say today that they do not want further treatment but tomorrow, 'Yes, please. Send me into Darwin. I want as much treatment as possible.' That is perfectly okay. It is really their decision. People have to feel confident with that.

Mrs CARLSON: From other communities, we understand that generally an individual's decision can still sometimes result from a conversation and other family members are involved. I want to understand if that is similar in Maningrida, that when those types of documents are discussed and signed to get the consent and the understanding, are the decisions still being made by direct family members? Is there a system?

Ms WOOLF: Not really. The staff who are having the conversation have a fairly good understanding of the family dynamics. James has worked in the clinic for a long time, and Charlie has been there for 48 years. They are always available to consult with. If we have any concerns, certainly we consult with the senior staff, who can always give us advice.

The dynamics are different probably for most families. Sometimes it is the patient who is making the decision. They feel very strongly to make that decision, and that has to be respected. It is not necessarily the family who makes the decision.

Mrs CARLSON: That is fantastic.

Mr CHAIR: Talk to us about palliative care and/or people who have finished up on country any time recently. What has their experience been like in terms of being able to access palliative care, pain relief? Has it been a smooth process? In some places, there has not been a lot of support. I am wondering if in Maningrida it is a bit better.

Mr GUNABARRA: Most of our families pass away in Darwin in palliative care. Now, we are starting to think that we will try and get our families back early so they can sit with the family. Most of them do not even make it to go back home. It is really hard.

We have a new palliative care building coming up near aged care so that family can sit around, go bush and be a part of the family. It is really hard (inaudible) has got a family passing away here in Darwin. We are going to try to get them back home for the time to finish up.

It is good that we have some people sent back home, and they stay at the aged care to be looked after—feed them and wash them. Then when they are very sick the doctor do the regular checkup and the nurse they talk to families (inaudible). Then the family won't make it in a couple of days, so they decide in the family what they want to do—take them back home or leave them inside the aged care. It is their choice. We can just help them to come back home. Their choice if they want to pass away in the bush or homeland, that is all right.

Most of the people are aged, born in a different age and sometimes scary, other (inaudible). They just go fishing. Most of them do not do exercise. Too many home white people do no exercise, walk in the bush. Most of them do not do that. Sports, footie (inaudible) we have a lot of young fellows playing. But we don't know; for me it's a walking time bomb.

Mr KERLE: You said 'a walking time bomb'?

Mr GUNABARRA: Heart attack. I am talking about heart attack. Maybe they play and are fit. We do not know.

Mr WOOD: Just to elaborate off that. With regarding recommendations of this—consideration regarding cultural safety is a big issue for the community. Also the individual, as in family through our kinships and family ties, in regarding that decision-making, if they wanted assistance—big decisions are always made by the family. A good example is, my wife passed away last year, through palliative. Between her and myself, we had been married for 30 years. We made that decision with our children that we would take her back home and let her rest in peace on her homeland. That is what I basically did, as her partner and husband.

That was her wish. Her children agreed to fulfil it, and that is what we ended up doing. We moved her from the palliative care unit in RDH and took her home by ourselves. Through the system, Mala'la, with pain relief and everything else, with the nurses coming out every day. We basically took her out to her homeland and let her rest in peace there.

Regarding past experience about the healthcare system, it is going to be challenging. You will need to have that trust with the existing services that are currently in play.

You got to remember, like we said before, that the language and communication barriers is going to be a big turning point regarding resource off the part of the operation of this, if it does roll out. You got to have that balance between cross-cultural communication as well.

The community members—there can be a lot of different understandings of illness and dying that they need to interpret and understand what that means about this whole process. Yes, it is going to be a big decision for community in whole, especially somewhere like Maningrida, where there is a lot of population compared to a smaller remote community where this could be an option for them, being on a smaller scale compared to somewhere like Maningrida where it is on a big scale. There are a lot of considerations that need to come into play. That is to address the whole cultural safety issues.

Mr CHAIR: We have heard a lot of the same things that you have said, repeated to us, across the Territory in different communities. We are very mindful of that.

We are starting to think more broadly—as we have from the beginning—about 'voluntary' and 'assistance', not just about giving somebody a medication to hasten their death but to help provide people with help in their choice to finish up well. I very much appreciate you sharing the story you shared with us.

Mr WOODS: The reason why—I will give you a good example. I am sure Lesley and Charlie are familiar with it and on behalf of David and Shane, they will be aware of it as a community concept regarding when we had community members who are sick and they get the assistance from the clinics in pain relief, that there is a fear with the family regarding getting that treatment and being superstitious about the needs of that individual.

That is where I am coming from about the cultural barriers and everything. The family has to be aware that the health service is not forcing anything, but it wants to assist in returning that individual back to the homelands like we mentioned before. That is the whole process to remove them from a metropolitan surrounding back to the homelands, like I did with my partner.

Mr CHAIR: We are trying very hard to separate out, when we have the conversations, healthcare to fix people; palliative care to help people with pain relief when they are dying; and then VAD as a separate thing again. We are trying to have that conversation regularly. It is difficult but it is useful to know whether there is any appetite for or interest in or opposition to the VAD idea itself.

Within Maningrida, you all represent, you are all leaders of different types for the community. Can you give us any sense for whether you are for it, against it, do not mind if someone else has it, whatever it might be? Any indication you can give us is very helpful.

Mr WOODS: It would be like what Lesley said. The community has not really put in any consideration regarding this service. We just take it day to day. If family get sick and goes into Darwin, then they fly back home, and then they go back to Darwin and fly back home. That is the health service. We want to try and improve on that. With this concept to be considered, there is definitely a lot of work that needs to be done on this and returning the individual to the homelands.

A good example with the West Arnhem, we have just purchased a four-wheel drive hearse to assist the community to return community members back to their homelands. That is the kind of logistics stuff we are talking about in assisting. I am sure the colleagues on the screen as well, representing their organisations, would support this as to how we can actually—as Charlie said—return people to their homelands instead of being locked up in a mortuary for months on end, just trying to get back home.

Mrs CARLSON: My question will be around what you have just explained. I am trying to gather whether it is more evident in your community—because you do have an amazing facility, great support services with the 24-hour medical assistance and stuff—do you think then for your community as to where it would be best placed, your priority would be more to continue to lean towards using service such as palliative care and enhancing that, rather than for individual community members to go down the path of using the voluntary

assisted dying and ending their life sooner when pain becomes too traumatic that they just cannot bear it anymore?

I am just trying to gather whether—because you have such a great healthcare system—you are still prepared and willing to use that model in your community?

Ms WOOLF: It took some years before advance health directives were even discussed. It is like an evolution, I guess. Because it is not something that has ever been considered it has not been discussed. I hear on the radio people talk about voluntary assisted dying, et cetera, but it is not something that has ever been discussed, that I am aware of, in the community. It may have been discussed amongst some of the balanda people, or non-Aboriginal people. It is certainly not something that is discussed.

I guess if it was legislated, number one we have to remember it is voluntary. It can be legislated and everybody can talk about it and hoo-hah about it, but at the end of the day it is voluntary. No matter what happens, no-one can force it on you ...

Mr CHAIR: No, of course.

Ms WOOLF: Absolutely not; it is voluntary. But I guess over the years then it may be that it is a discussion that, say, a doctor has with a patient or with the family. I do not think that will happen next week if it was legislated next week. That will not happen; it will take time before it even becomes part of the conversation.

As I say, I do not believe it is being discussed in community because it is not something that has been on our radar.

Mr CHAIR: You may be aware the Northern Territory did have a voluntary assisted dying, a euthanasia law, back in 1995. It is different from what the current laws around Australia look like in some ways. Does anybody recall there being any conversations at that time? I do not know if anybody is old enough to have remembered them.

Ms WOOLF: Charlie and I are. No, I do not believe so.

Mr WOODS: I remember Dr Nitschke and all that drama when they made the law and everything. Me, individually, I had it in the back of my mind back then that in a supporting way, yes, but then, as Lesley and we have been saying all morning, it is up to that person. It is voluntary. If they actually want to do it—regarding their legal technicalities, the blaming game, assisting with your carers and your staff, the health service. That written wish is actually from the individual itself.

As Lesley said, it has not been really spoken about in community regarding any assistance ...

Mr CHAIR: Our process out in communities has been two ways as well. We have been answering a lot of questions about what that model might look like. To give you an idea about that, you can obviously go back and look at the report. The sort of model that is proposed in the 2024 report is similar to what is in the rest of Australia, which operates in basically four steps. Somebody who is terminally ill has full mental capacity to make a decision can go to a doctor. That is the first stage.

If that person says that they are a viable candidate for VAD, then there is a second medical person who has to sign off on it as well. Then after that, there is a process of written consent and witnesses, and a waiting periods in between all of those. Then there is the final stage of a medical team that can help with administration and helping people to pass on. The details vary a little from place to place in terms of time and whether it is a doctor, a practitioner nurse, where it happens et cetera.

Nothing happens like that, as you pointed out. Also everywhere in the country, once the law has been passed, there has been a standard 18-month window for implementation whilst everybody figures out how to make it work, nuts and bolts, as well.

If anything were to happen, certainly there would be lots of time for conversations still. There is no cause to fear that anything would happen overnight.

Mr WOODS: With that, can I ask why back in 1970 it was not recommended as part of the other jurisdictions until now?

Mr CHAIR: It was not quite that. In 1995 a law was passed in the Northern Territory parliament to allow voluntary euthanasia. In 1996 then the Howard federal government, a private members' bill, by a gentleman called Kevin Andrews, was passed and that overturned that law. It actually stopped the territories of Australia from making euthanasia laws. That was the situation until 2022 when the federal government changed that law back, allowing territories to now make voluntary euthanasia laws.

In the meantime, starting from 2017, Victoria was the first state that decided to pass a VAD, voluntary assisted dying, law. Now, today, every state and territory in Australia has a VAD law except for the Northern Territory. The newest one is the ACT one, which has not actually stated yet. The law has passed but people will be able to access it from the end of this year for the first time.

All of them look pretty similar, with some variations, some sort of tweaks, if you like, here and there. They are broadly consistent.

There was a long period when the Northern Territory was not allowed to make a law on voluntary assisted dying. Now the sense is that there are people who want a law in this space, which is why we have been directed to look into that report and recommend where to go next.

One of the things that was suggested was that people have not had enough conversations out bush in remote communities, with the 30% of Indigenous people who are Territorians as well, about how they feel about all of this. Any insight we can get on that adds to the conversation.

I have a bunch of people online, I'm mindful. Does anybody who is online with us want to say anything. I see Kira and a couple of others there. Is there anything you would like to chip in with?

Mr KERLE: In other places we have walked people through the proposed model—the four stages. Is it worth going through that?

Mr CHAIR: We can do. I am mindful we have limited time. I might let you ask a couple more questions.

Mr KERLE: I have two questions. One is specific. We have heard a lot when we have gone to communities about finishing up well on country, which is exactly what you guys are talking about. From what you said, it sounds like you guys have the best setup so far. We have not heard about a four-wheel-drive hearse anywhere else. It sounds like you are doing it regularly and quite well. There are some communities we have been to where they do not have the option because they do not have the infrastructure or the organisational capability.

As background, we will write a report and it will go to the government, and the government will decide whether it wants to do a bill to make legislation. What we can include in that report is everything that is said to us.

Are there any legislative barriers that make it hard to finish up well on country in terms of withdrawing from treatment, making sure the next of kin understand? In an Indigenous context, it is different to a balanda context. In balanda, it is husband and wife, kids; whereas, out on community it is much broader. Are there any legislative barriers to finishing up well on country in terms of withdrawing from treatment and going out to community knowing that it will probably be the end of someone?

Mr GUNABARRA: If someone, say, from the community, has hundreds of (inaudible) here in Darwin. When that person is unwell, what they do is they send the person back home or they do the teleconference with family back home. Staying with us we've got whole family, you know. The doctors with the information, he comes over home and just talks to family. He says, 'We will probably watch him and it will be a couple of days'. People will understand.

Before it was really hard. We kept them, and there was a lot of drama from family—argument—but now everybody understand that when families—basically they need to go back and settle it with all the family, and they make a plan, if this person is going to pass away we're going to send them back home. That is where he belong, homeland. They do a lot of ceremony, dancing, you know.

I believe the community, a one-day funeral is not what (inaudible) It depends. Extended family is probably out of community, flying in for sorry business. We give them time, and then the day we have the funeral. Aboriginals running really good, people understand. We try to get more family, language group there.

Mr WOODS: To go off that, regarding the challenges in remote areas. You already mentioned me make up 30% of the Territory—in remote areas, the challenges could be the people in remote areas may have trouble accessing the service due to distance. Also there is no guiding cultural safety principles built into that legislation. In the other Australian states and territories, consideration may be given whether cultural safety should be a guiding principle in the Act. That could benefit this legislation.

Mr CHAIR: Can you elaborate on that? What do you mean by that specifically? For example, the 2024 report, Appendix 9 of it just says things should be done in a culturally significant ...

Mr WOODS: In best practice in cultural safety, Maningrida goes on a lot about cultural practices, and there is a lot of public policies that do not address public cultural practice. That is what we are talking about here. That is your big barrier right there. In your policies, the policy-makers need to understand how to do best practice.

Mr KERLE: Are there any specific examples that they should be aware of? For example, if you are talking about finishing up well on country, what is a specific thing they would need to be aware of?

Mr WOODS: Understanding that the people might not even have the access to it. How will you give that person that free access to it?

Ms WOOLF: Just to put that in context, we have 30-odd outstations. Some are an hour-and-a-half to two hours away. The roads are very often cut. We have \$120,000 per year to run that outstation service. That does not even fund one position.

We provide services out there during the Dry Season, but there is not a lot of opportunity all year round. From a cultural perspective, if we would facilitate better services on the outstations, that would make a big difference.

Mr KERLE: Lesley, you might be better placed. When people are going out to finish up well on country, are there any legislative barriers—white balanda laws—that make it hard to do that, that we could look at in our report? Or is that all working pretty well?

Ms WOOLF: Not necessarily, only the fact that we have limited services to the outstations. We have a nurse, a doctor and a community worker—usually from that community or with ties to that outstation—go out every week and provide a service to a particular outstation. We do not go to the same one each time. Each outstation might get one or two visits in a Dry Season but that is it. Basically, in the Wet Season, it is a matter of responding to requests. Somebody rings up and says they are sick. If we can, we get to them. If we cannot, it is a matter of CareFlight getting a helicopter or a plane out, which is not always possible.

They are not legislative restrictions, but they are restrictions. As Charlie said, people are much healthier on outstations, but the services out there are very limited.

Mr KERLE: I have a different question. I have asked this to all the communities we have gone to. The community has not had a chance to form a decision on VAD yet, because they have not had a chance to discuss it properly. That is okay. As representatives, do you have an opinion on say, if this was to become a law that was passed, if my neighbour in town, in Palmerston—they are not Indigenous or a cultural person—was to choose VAD, would that be offensive? Would it cause harm to people in your community? Or is that okay? That is their choice.

Ms WOOLF: We would not know, would we?

Mr WOODS: Us being in Maningrida, and someone living next door to you in Nightcliff or wherever, we will not know.

Mr CHAIR: Most people have indicated they do not mind if it not for them but someone else. If it is their choice, they can have that choice.

Mr WOODS: Like I said, back in 1997, me individually, I supported it. But that is me individually. That is not the 180,000 Territorians living in the Territory.

Mr CHAIR: We are not here to do a referendum on everyone in the Territory. Other people have tried to gauge that support. We are working from that basis.

Mr WOODS: With this thing, on another note, is there going to be guidance for Aboriginal and Torres Strait Islander people regarding this? Are you going to have additional guidelines to ensure the equity to access VAD?

Mr CHAIR: That is exactly what we are trying to interrogate here. The whole point is we are trying to establish whether or not people are interested, they would like access and how we can make sure, if there is a law, that there would be viable access. What we are generally finding is that—we have found some instances of people saying that when they are in end-of-life situations that maybe there would be some interest, depending on the individual.

Mr WOODS: That will include information on the actual process ...

Mr CHAIR: Yes, the process ...

Mr WOODS: ... including options of assistance to offering actually returning to country ...

Mr CHAIR: Returning to country is not ...

Mr WOODS: ... like I said, with the four-wheel-drive hearse?

Mr CHAIR: Returning to country is not considered in the existing documents. That is why we are asking so much about it. Those things have not been covered in the 2024 report about people returning to country or, for example, any barriers to returning to country, which Matt was asking about.

One of the things we were curious about with you guys, have people been able to withdraw from treatment when they want to, to get back in time? Has there been any prohibition for people who may be stuck in hospital and unable to discharge themselves? Is that something you have ever come across?

Ms WOOLF: People have not always got back in time. That is disappointing for us as well. One of our staff deteriorated quickly and did not get home to die with her family. We were devastated because we all knew her very well. She worked for Mala'la for a long time. We were upset that she actually could not die on country and could not die with her family.

Providing communication is good between the system and the community. There is no limitations in terms of people coming back. People have to have their dying wish, basically. If their wish is to die on country, that certainly should be honoured in every way.

My query is probably, from a personal view, is would it be available in Maningrida, or would it only be available in Darwin? Because people do not want to come to Darwin to die. Also, if they said, 'Yes, I want voluntary assisted dying' but the day before they changed their mind, how does that sit?

Mr CHAIR: I can answer the questions fairly quickly. The second one is anyone can change their mind right up until the last minute. Nothing is binding. If you go through a process of seeing a doctor, the waiting period and a second doctor, the written consent and witnesses—all the way through—there is nothing to say that somebody cannot withdraw at any time and say, 'I have changed my mind'. That is ironclad.

In terms of where this would happen is one of the big questions. As we say, we estimate that maybe 10 to 20 people a year in the Northern Territory, statistically speaking, might want to take up this service. We would not have a service based everywhere for everyone. The whole point is that there would be some sort of service that would come from elsewhere to help out with these things.

Whether that was a standalone centralised service, or part of the existing network of doctors and nurses and people who wanted to participate in this—those are all things that are still being thought through, basically. There is no definitive answer on it. When we asked the Health department, for example, about implementation plans, similarly it is too early for that sort of thinking.

We are trying to make sure that anyone who does want access to this, or has an opinion about this, is able to share it with us so we can share it with the rest of the parliament.

Mr KERLE: We do not want to have any legislative ...

Mr WOODS: Going off what Lesley just said, a prime example was my partner, as I said. Once we found out via the health service that treatment was not going to work and vice versa, then we made that decision to withdraw from the palliative unit and go back and return to country.

Mr CHAIR: I am grateful that you shared that story with us because it must be difficult to share, obviously. It is the kind of information we are looking for, in some ways.

Can I ask, James, when you went through that process, was it relatively straightforward or did you hit any road bumps with trying to make that all happen?

Mr WOODS: The road bump I hit was I was going to lose her. Also, as I have been saying, the communication of actually getting that service to prevent it was the biggest bumps. That is why we made the decision because it was pointless to remain in hospital and not get a service. Basically, we wanted to free it up and return to country.

Mr CHAIR: So the doctors and all that were all consulted?

Mr WOODS: They consulted everyone. We basically had our time to ourselves and kicked everyone out of the room and made that choice together.

Mr CHAIR: When you returned to Maningrida you had adequate support and help when it came to pain relief?

Mr WOODS: Yes, and a bit more work of course. The community as well with brother-in-law there. That support was always there. My immediate family basically went back to the homelands and did our preparations and everything and then brought my partner out and gave her her last dying wishes. Had the funeral a month later.

Mr CHAIR: We would like to help other people's last wishes be honoured as well, whatever they are. For some people that will mean choosing a voluntary assisted death if they are terminally ill. For other people, it won't. For some people it will mean being able to hopefully return to country in an easier manner if they are having any impediments to that. All of what you are sharing today with us is really helpful, and we really appreciate you taking the time to come and talk to us about it.

In terms of what happens from here, we have another week of being out and about this week based around Tennant Creek. This week we will be out and about in that sort of region, and then starting next week, our submissions will close and we will start to go through all the data and information.

Mr JONES: My wife is not from the Northern Territory. She is from Western Australia, but she died here on 29 May and her choice, she told me I need to bury her here in Maningrida, but I told her she had to go back to her home. She went back to Western Australia in Derby, and she is buried there—not buried, but she waited for me until I buried her there. To me, what I hear today, in the wild, people die they didn't return to their home. Their home is Maningrida. They are buried there. They lived there for their life.

Before this legislation came along with Bob Hawke, take the rule and people going in their homeland. But in the wild I give you (inaudible) and all the story what I got. People in 1988 buried in community not in homeland. Their home is Maningrida.

When intervention came along, and people that is how they are moving out in their homeland, but in the wild they are buried in community Maningrida. Since 1986–87 I seen we had two burials. One in airport(?) and one in bottom camp. (Inaudible) all the loved ones are right there. They came back home for a reason, but their home is Maningrida. They grow there, they work there, and live there for their life.

When the government came along it changed everything and take our loved ones back home. But it is real good, you know. To me, like I love my people to live in Maningrida, at home, but the problem is we've got like, with Mayor here, my other (inaudible) here, and we keep on fighting for our boys; one for our community, two (inaudible) burial. That is my real worry. My wife passed away so they say a choice, but I told her you have to go back straight from where you came. I meet my wife and we sit together for 35 years, and I sent her back home to Derby. So thank you.

[Multiple people speaking.]

Mr CHAIR: That is a very good story.

Mr GUNABARRA: There is something I need to know. With patient (inaudible), depends on hours, minutes seconds, depends how fast and strong the illness is, if it is cancer or whatever, they go a little bit faster, it depends.

Back in 1976 I was a health practitioner, we had about 200 population there. And like he said about burial, a lot of people came in from all different homelands and different language groups. We had the biggest burial there. Many people came from a long way from east, south, north, west and all buried there since there from 1950s when Maningrida was growing. It was run by the welfare mob, and then it became a settlement and now it is a community, it keeps changing.

So many of them were buried next to the houses. I believe that now has changed, so you cannot bury your family there. For babies, we buried them there because they next to you; you can sit and watch them—watch the grave every day. It is really sad, but now the law change and everybody buried at public cemetery, but people do not like it. We have different language groups and people from the homeland want to bury them home—take the family back homeland; that is where they are from.

Mr CHAIR: We understand how strong the connection is for people to want to be out on country when they finish up and to be buried in the right place as well. These are all the kind of things that, to be honest, have not really been dealt with in the VAD discussion before. It is useful for us to try to understand how the two things intersect in different places.

Thank you very much for your time today. We are grateful for your coming here ...

Mr GUNABARRA: Just a quick one ...

Mr CHAIR: Absolutely, please.

Mr GUNABARRA: One time when I lost my dad and there was law. The police came and tried to take the body away. Straightaway, I said, 'Hey, hang on, that is my dad'. We need to have respect, (inaudible) a long way—get all the family to come with us. It has happened; a friend passed away at night. We need to know in the morning. Everybody there, there is sorry business before he removed to a mortuary. Got our family in there.

Mr KERLE: Thank you for that. That is a great example of a specific thing around cultural safety that we should take account of. If there are any other specific examples about cultural safety, we are open for witness submissions ...

Mr CHAIR: Until the end of this week still.

Mr KERLE: Please, please, make a submission so that we can include that in our report, because it is ...

Mr CHAIR: Yes, it is helpful to have any of that stuff because, at the end of the day, the law will be the law, but there will be a whole lot of other things around it that will help inform how the law is applied. If we can learn some of those things that would be really great.

Ms WOOLF: If it is legislated, then we would develop policies then as to how it would be managed.

Mr CHAIR: Yes, there will be a law and then regulations, policies and implementation guidelines. Our job is simply to write as comprehensive a report as we can, with perhaps some drafting instructions for model legislation and recommend that to the government. Once that is provided, then we will see where it goes from there.

The more we can gather at this stage, the more voices we hear from, the better chance we have of, hopefully, doing something useful for everybody.

Mr KERLE: At the moment it just says, 'be culturally safe', but we do not have any instruction on what that means. That is a good example. If someone passes away, the body has to be left there until the cultural processes have happened. It may not make it into the law, but if it is in our report, then when they are defining the policies they can have regard to the report.

Mr JONES: In a way, our old people, they did not really send our loved one in Darwin—to have voluntary, to dance and make them celebrate and put them down—that is long time. We was to keep on keeping our

culture strong. This hollow tree, when put our loved one, all them bones in the hollow tree and there was dancing and leave it for many years. Happening today.

Mr GUNABARRA: Yes. Thank you.

Mr CHAIR: Shane, David, Charlie, James, Katherine, Lesley, Kira—I am sure I have forgotten a couple of people who are online. Genuinely, we do really appreciate you coming down. We would have like to come to you. We know that it was not a good time, but we did not expect that you would all be coming to us. We are grateful that everybody made the journey. It has been helpful for us as well. Please, if you have time, also consider providing something to us in writing as well to fill in any gaps or any extra thoughts you might have.

Ms WOOLF: Thank you, it is much appreciated.

Mr CHAIR: Thank you so much, everyone.

The committee concluded.
