The committee convened at 11.08 am.

INQUIRY INTO VOLUNTARY ASSISTED DYING
St Matthew's Anglican Church

Rev M HALL: Good day, everybody. We want to welcome you here in Ngukurr for this meeting. I want to open up and explain. You can explain later on what you came for. Before we start off, William will have a prayer first.

[A prayer was read.]

Rev M HALL: I want to acknowledge the Yugul Mangi traditional owners, the seven tribes of this community, past and present for being here in God's spirit. Craig is going to read a prayer and then we will hand it over to the rest.

[A prayer was read.]

The INTERPRETER: [Kriol spoken.]

I just told them I will be interpreting in English and Kriol. I have to be professional, accurate and impartial.

Mr CHAIR: Thank you, everyone. First of all, I respectfully acknowledge the traditional owners of this country. We all pay our respects to the elders past, present and emerging.

Thank you, everybody, for hosting us today, for inviting us to come to Ngukurr. My name is Dr Tanzil Rahman. I am the Chair of the parliamentary committee.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: We are here today to talk about voluntary assisted dying, or what some people call VAD.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: This can be upsetting to talk about for some people because we are here to talk about death and dying.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: If anybody feels upset at any time or they need support or want a break, then tell us and we can take a break.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: We also have support services, if anybody feels upset. We can share those details with you or we can also talk with you.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: We all know that some really sick people feel a lot of pain and they suffer when they are really sick.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: We are here to talk about people who are so sick that they are going to die.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: It is important to understand we are not talking about people who are a little bit sick or can be treated; we are talking about people who are so sick that doctors think they are going to finish up.

The INTERPRETER: [Kriol spoken.]

Unidentified speaker: (inaudible).

Mr CHAIR: At any time if anybody wants to ask a question, you can ask a question. I am just introducing the subject to start with, and then we want to hear from everybody what they think.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Is that okay with everyone?

[Multiple people speaking.]

COMMUNITY MEMBER 1: If we like this, whatever you would like to do, will it be passed through parliament?

The INTERPRETER: [Kriol spoken.]

Unidentified speaker: (inaudible).

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Do you want me to answer?

The INTERPRETER: I will answer. [Kriol spoken.]

What is the other one?

Ms WILLIAMS: There is a community drop-in this afternoon at the council offices.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: We are starting in the church hall and then in the community centre for community and also the council offices as well. Meeting all the people who are working in council, aged care, disability—all of them mob will talk to you then as well.

Before I forget, it was my mistake, I should have let all my colleagues introduce themselves.

Go ahead and introduce yourselves.

K McNAMARA: Hello, my name is Kat. I am one of the members of parliament. We are from different parties, working together on this.

Mr YOUNG: Hello, my name is Dheran Young. I am also a member of parliament. The area I represent is the seat of Daly, which takes in Daly River, all around Wadeye, Peppimenarti, Palumpa, also Berry Springs and Wagait Beach. I am also a colleague of and work closely with Selena Uibo. You probably know Selena, the local member. We are in the same party as well.

Mrs CARLSON: I am Oly Carlson. I am a member of parliament as well. I represent an area close to Casuarina and the hospital, next door. I have been a representative of the Anglican Church, when I was a child, representing Australia actually.

Mr KERLE: My name is Matthew Kerle. I am a member of parliament. I represent part of Palmerston, Moulden and Woodroffe, if you have any family that stay in Moulden. I am part of the committee, and I am here to listen.

Mr CHAIR: We are all here today to listen to what you have to say, that is why we came here today.

Let me tell you what we want to ask you about first. There is a new idea across Australia called voluntary assisted dying (VAD). It is about trying to help people who are sick when they want to finish up.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Every other state and Territory in Australia has a law for VAD, except the Northern Territory.

The INTERPRETER: [Kriol spoken.]

Rev 1: (inaudible).

COMMUNITY MEMBER 2: (inaudible). I remember my mother was very sick. She had to make her own way back, pay her own fare, came home in a taxi.

Unidentified speaker: (inaudible).

COMMUNITY MEMBER 2: Through the Wet Season with the boat. She was in a wheelchair, here for three days to live with us. She was really comfortable to pass away. I was speaking to my mum through that day and that night. We lost her on Sunday. She came on Friday and she passed away on Sunday.

I know what you are saying, but it is our choice for our people—our houses, our loved ones, we give them that. We give them (inaudible), a comfortable spot and comfort them. We come with visitors. Every family comes to see that person before they leave. So we have a difference. My opinion for this, I say no for my people.

Mr CHAIR: The first thing with this to remember is it is voluntary. Nobody has to do anything. This is a choice.

COMMUNITY MEMBER 2: Voluntary.

Mr CHAIR: Nothing is being imposed.

What we also want is for people to have a chance to finish up with their family and not suffer, wherever that is.

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

The INTERPRETER: That is why they need more explanation, not only from one person; from everybody.

[Multiple people speaking.]

K McNAMARA: Even if the answer is no, we still write down you say no.

COMMUNITY MEMBER 2: I just gave you a picture of what happened to our mother—my older sister is here—Melissa's great-grandmother. That is what happened with our mother when she was very sick. They could not keep her in the home anymore at Red Cross in Katherine, so she had to pay for her own fare down to come back to us (inaudible) comfortable to live back home (inaudible).

Mr CHAIR: Sometimes there are other people who feel when they are suffering too much and they are in too much pain and they can no longer live properly, they want doctor to help them, so they are not suffering anymore. That is what this law is about—only for people who choose.

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

Rev 1: Whatever your approach, that story—it may concern you, but it does not concern us. Taking someone's life is a criminal death. An example of what you have done, what is done against you (inaudible). Keep that in your mind; it is coming (inaudible).

Rev M HALL: Can I say something through the Chair. I introduced myself anyway, but we (inaudible). Reverend Marjorie Hall and William Hall and Craig Rogers, the church.

We were thinking about you say 'voluntary' thing, but then when we think of the voluntary thing, how do you go about it if someone is in a coma?

Mr CHAIR: I can answer that question for you. The way this—I will go back one step. Last year this report was produced, not by the government but by doctors, lawyers and experts.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: We were asked to judge this report—whether this report should go forward and whether or not we should make a law.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: I will answer your question. In this report they tell you how somebody could use this law. The way it will work is this: if somebody is very, very sick, they have to go to a doctor first—not in a coma; they have to be conscious in their mind. They have to be able to give consent. They ask the doctor, first of all, 'Am I sick enough to be able to access this?'

The INTERPRETER: Can you repeat that again?

Mr CHAIR: Sure.

If people wanted to access this, according to this report, they go to a doctor and they say to the doctor, 'Am I sick enough? Am I going to finish up within a year? Can I access this voluntary assisted dying?'

The INTERPRETER: [Kriol spoken].

[Multiple people speaking.]

Mr CHAIR: Well, it is three stages.

COMMUNITY MEMBER 2: (inaudible).

Mr CHAIR: I know you understand; I want to make sure everybody understands.

In this model they present, there are three steps: one, you ask the doctor; then, two, another doctor has to say they agree or they do not disagree; then, the last one, the doctors and nurses can help you, if you want to use this, but not just anybody in a coma or no-one.

[Multiple people speaking.]

The INTERPRETER: [Kriol spoken].

Rev M HALL: That person feels the pain. You are talking about pain and that person.

Just going back, we are doing that with the doctors. One patient already can get the consent from the doctor. I gave my story and I said I do not want to donate my—you know what I mean?

Mr CHAIR: Organs, yes.

Rev M HALL: Organs—I want to be at home to be buried and to die with my family. It is really hard. In Darwin, there is only one palliative care house on the back of the Darwin hospital. We need more, or maybe we have our own clinic there. That is something to (inaudible) but not for people here, to be coming home from hospital and have that palliative care in the community.

Mr CHAIR: That is a great point. Yesterday we talked to the Health department. We talked to the Medical Association and the doctors and we all agree that we need more palliative care and we need more palliative care out on country. If this becomes a law, we need even more palliative care—we know that.

The INTERPRETER: [Kriol spoken.]

COMMUNITY MEMBER 2: Instead of dying in the hospital, we die at home.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Let me give you an example …

COMMUNITY MEMBER 3: (inaudible).

Mr CHAIR: Can you repeat that? I did not hear clearly.

COMMUNITY MEMBER 3: This goes to a person who is in that dying situation. It is that person's choice.

Mr CHAIR: That is exactly right.

The healthcare system is to look after people. This is separate and this is to help people finish up, if they want.

Let us use an example. Let us say somebody has bad cancer. They can still think straight, but they are now sick and suffering. They are in too much pain and they do not want to die in the hospital. What this might do, if there was a law like this, is rather than somebody having to die in the hospital, before they get too sick and cannot come back to country, we could bring people back to country. Once they are in country surrounded by family, friends and loved ones, if they need help with palliative care or if they need help separately with VAD—with voluntary assisted dying—somebody could help them on country, rather than always in a hospital. That is part of what this is about.

The INTERPRETER: [Kriol spoken.]

Unidentified speaker: (inaudible) palliative care.

Mr CHAIR: It is part of our remit. The point is that it is clear. Sorry, I do not want to speak outside of—palliative care is part of this discussion, so it is fine to have it. We are obviously being asked about it.

Rev M HALL: In our culture, life span. What the doctor consent—I tell the doctor, 'I am going to speak to my families'. There is a procedure for us to talk to our families. I am not going to make that agreement or that story. I have to ask my husband, my family, my children and siblings. It is a family thing. I just tell them, 'I am going to speak to my family first and explain what is going to happen'. I have a couple of doctors. They have got my stories already. (inaudible) families what is happening with my health. Already my story is in with the doctors. But, really we do not want stabbing with the needle.

Mr CHAIR: Nobody who wants something does not have to have it. That is the first thing we should make clear again and again.

Rev 1: Even if the person is very sick and cannot talk?

Mr CHAIR: Even if they are sick, nobody can receive this treatment. In the Northern Territory, nobody can have it; there is no law. But in the rest of the country if somebody is sick and two or three doctors agree and they ask, then they can have it—but only then.

Rev M HALL: Consent.

Mr KERLE: Yes, that is the one—consent.

The INTERPRETER: [Kriol spoken.]

COMMUNITY MEMBER 1: Can I ask you—one, two, three, four, five, six, seven—are you afraid of death?

Mr CHAIR: Sure, I am afraid of death.

K McNAMARA: A little bit, yes.

COMMUNITY MEMBER 1: I am just asking: are you afraid of death? Everybody should be afraid of death. It comes under every culture in this world. You have got to follow certain rules and laws to handle all this time. As for the Aboriginal people, we got two—we got Christianity and we got our own law. When it comes time of gathering the people, or making law and decision, one man (inaudible) and one family, and other family we got—what?—that control. They have got to handle everything—when we come and bring the body here, we give them to the church.

European culture is very, very hard for us to understand. We need simple explanation and a form of rules or regulations for our own area here at Ngukurr. If my brother dies at Borroloola, without family there, they are not going to bury him. They are going to wait. We call it two-way—and dying, all that comes under ceremony. If we do certain things that is wrong to us through that culture, you will cause some trouble for that.

It is very hard for us sometimes to handle this kind of—you know—especially death. If you are very sick and then (inaudible) if we needed it (inaudible). You are going to be (inaudible). We give you this thing now, but sometimes it creates …

Unidentified speaker: (inaudible).

COMMUNITY MEMBER 1: You have got to put all the names and (inaudible) for everybody when you make a rule. Do not write it. Do not take it to parliament and get the thing. We write the thing here for the people here at Ngukurr. We write that thing and put it down. If you have got an opinion then (inaudible), not suitable for our parliament or whatever, but if we write it down here (inaudible), label all those rules and things here, I will give it to you (inaudible). If we are pleased and say that is good then you can make it for Ngukurr area.

Mr CHAIR: Do you want to fill in for everyone?

The INTERPRETER: I will rephrase. [Kriol spoken.] What I say is a sign of respect, because he is my great-grandfather. He is saying that there are two cultures—there is religion and there is Aboriginal tradition. It takes time. That is why everyone here, they decided not to accept the VAD because family will have to make a plan. If that person passes away tomorrow, they will be shocked and it will be a rushing plan. Sometimes it helps family when that person passes away in a couple of days within their own time. It gives us time to do our role as part of that—their role.

He also asked if we make our own policy for our own community and we give that to the government, to you mob, and you can see clearly what we want for us and what we want from you. We put the two policies together and try and match what is right.

Mr CHAIR: On your last point, we would welcome anything that you write, as a community, and give to us. We, in fact, did write to this council and every council across the whole Northern Territory—all the traditional owners, all the land councils—asking everyone, ‘Please tell us what you think’. All the information is available and if you can write down what you think and give it to us, it is helpful for us.

COMMUNITY MEMBER 1: There are funerals, burial sites. You have got two (inaudible) the hospital (inaudible). We do not want them. That is the first rule (inaudible). That is no good. But on our cultural side we bring them up, we use our (inaudible). Then we come back, take the coffin, come up here, hand it over to the Christianity side. A lot of us went to (inaudible). We have funeral service (inaudible). We do our cultural side. There are two things happening, but (inaudible). We believe in Jesus, so that is two things (inaudible).

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Some people worry that if we make this law whether Aboriginal people in remote areas can use this. I can hear you are saying even if we make the law, we do not want to use this. That is okay; you do not have to. Nobody has to; it is voluntary. Nobody has to use it.

But what we also want to know is if a law like this gets made—let us say a law like this gets made, does it upset you? Even if you do not use it, does it upset you? Or are you okay if somebody else wants to use this? If somebody else chooses to do this in wherever—another community or in Darwin—is that okay for you or does that also make you unhappy?

The INTERPRETER: If other communities accept this, do we have to make our decision to accept …

Mr CHAIR: No.

The INTERPRETER: We go through the consent?

Mr CHAIR: That is right, yes. All this is we are asking everybody across the Territory what they think about this.

Mrs CARLSON: It does not have to be community as well. It could be just one person …

[Multiple people speaking.]

COMMUNITY MEMBER 4: I know you have come from a different Assembly from Canberra. I want to know how many communities have you visited already within the Territory?

Mr CHAIR: Today is the first one; just starting today.

[Multiple people speaking.]

COMMUNITY MEMBER 4: Otherwise, really to me, because you are the person who is making the (inaudible) and that document has never been seen before. Really, by us, we do not have enough information to give to you. We need some time to work on it. We are going to have to get someone from outside to work with us and go through the document. We need to understand how we will move forward for this, with this document now. You have until September to report back to the parliament in Canberra. We need to get someone independently to talk to us and go through that piece of policy that you are already doing. Can we do that?

Mr CHAIR: I do not see why not, surely.

COMMUNITY MEMBER 4: Then you can feed back.

Rev 1: I think you are going back to the government. This is not government rule or (inaudible) here. We have got to make the decision (inaudible). They are pushing with a lot of things (inaudible). The answer is N-O—no. That is it. That is complete.

Rev M HALL: With the VAD, what support have you got already in place other than the other states? What kind of support things, like outside?

Mr CHAIR: Yesterday we spoke to the Department of Health and we also spoke to the AMA (Australian Medical Association) which is all the doctors. They think, and this report thinks, that the majority of people in the Northern Territory want a law for VAD for people who want to choose it. They think that the doctors and nurses we have now and the systems we have now and the rules and laws of other states mean that it can be safe, so that if somebody wants it they can have it, but if you do not want it, also it does not have to affect you. That is the thing. The question is whether or not there should be no law; or whether, if there is a law, you are interested in the law. Does that make sense?

Rev 1: I just said something here.

Mr CHAIR: I heard.

Rev 1: The answer is no—finished (inaudible).

[Multiple people speaking.]

Mr CHAIR: Yes, I hear you loud and clear.

K McNAMARA: I hear that you are saying no. But just to also explain that if someone chooses VAD, it is not just in a hospital; it also can also happen here. If people want to finish up on country, then they can do it at home.

Mr CHAIR: That is the thing. This is about taking people out of hospital.

[Multiple people speaking.]

Rev 1: (inaudible) person says yes for the pain, the family is going to say no.

K McNAMARA: Yes, a family decision.

Rev 1: If one person—if you vote for one person, the answer is no. The rest of them say no.

Mr YOUNG: Bobby, I am Dheran. We have met a few times. Just to respond to your question about it. The government, the Attorney-General—it is with the Northern Territory Government at the moment and the CLP government are in. There was this independent report done last year that was handed to government in August.

The Attorney-General—the lawmaker, the minister—sent this report for us to go out and do consultation work with Aboriginal communities. Unfortunately, we do not have a lot of time to do this. There will be a report done by September to give back to the Attorney-General and then they will then make a decision around that. Because the government have told us, we have got rules we have to work within; we cannot do anything independently, as was suggested before. The work we are doing now is going around to communities. Tomorrow we are in Borroloola, and we are going to other communities down in Central Australia. We do not have enough time to get to every community because the government has put the terms of reference together and have not given us enough time. We are trying; we are out at the moment consulting with who we can.

Does that answer that question around the independence?

COMMUNITY MEMBER 4: Do you need some feedback from our community?

Mr YOUNG: That is right. We are trying to get as much feedback as we can, yes.

Mr CHAIR: Bobby, part of what we want to do is—not much consultation has happened before with this report, or anything before, asking communities about what they think about VAD. That is why we at least want to ask as many communities as we can. Tomorrow we are in Borroloola; next week we are in Barunga, Beswick and Numbulwar; the week after we are in Papunya and Alice—we are doing as much as we can this month. In September we will take everything we have, whatever it is, and then try and report back to the government this is what we heard from the communities.

We already know what a lot of people think in the big cities. In the big cities a lot of this is already there, but people did not talk to people in community. That is why we are out here trying to learn.

I hear loud and clear that you are saying, ‘No, not for me; N-O.’ That is absolutely fine; that is not a problem. The thing is if no is how you feel, then no is how you feel. But there are other people in other places who say yes. How many people say no and how many say yes; and is it okay if some people say yes and some people say no; or should there be no law; or should there be a law that some people can choose but other people can say, ‘No; not for me’?

The INTERPRETER: If the number is higher than no, then you will have to go forward with the law.

Mr YOUNG: Not necessarily.

Mr CHAIR: Not necessarily, but on that issue—let me explain that. This report asked many thousands of people. About 80% said yes, they want it for a law. But this report also said that they did not get to enough remote communities to also ask remote communities. That is why we are getting extra information by coming out to remote communities. We know a lot of communities do not want this, and that is okay. But we want to know how many communities do not want this. We want to know if some communities might want it or if some communities do not mind—‘If it happens fine, but it is not for us’. That is what we are trying to learn.

COMMUNITY MEMBER 4: It is actually happening in other states.

Mr CHAIR: Every other state in Australia.

COMMUNITY MEMBER 4: It is already working, but in the Territory not yet?

Mr CHAIR: Not yet.

COMMUNITY MEMBER 4: It is up to us to be part of it; the reason you are asking us whether we support the document or not.

Mr CHAIR: Pretty much.

COMMUNITY MEMBER 4: So really (inaudible) that document, you do not want to go through that. Find out what the others are thinking. My issue was that I ask you in the first place, but you already answered my question.

Mrs CARLSON: Maybe it is not a question of whether you support VAD or your choices of palliative care. What we are trying to understand is what your view is on VAD and how the government can then go forward in helping all the different parts of the Territory. From today, I understand you probably would not use it here; you want more of a family model that you would return to country and have palliative care.

COMMUNITY MEMBER 4: Put it this way, we are clear that we are not ready to go that line, that is what (inaudible) said. We are not ready, but we need to have everyone informed so that we know what will come.

We know that the government department today is tricky for Indigenous people (inaudible). There is a strong commitment from the government (inaudible). A lot of important stuff went through; I think you have already seen it. A lot of our elders were talking. It really is for us that we need more information and we need to study that more. We want to support it, but we need more.

The INTERPRETER: [Kriol spoken.] Even though we are a no, they will still give help through other services—right?

Mr CHAIR: Yes, that is right.

The INTERPRETER: It is not no and full stop; it is no and reasons why, and you need to tell them. [Kriol spoken.]

Rev M HALL: If it is happening and everybody says yes for the Territory, we would like to see the guardianship to recognise more. When our people go to homes, they go to that guardian thing and we have no power to bring them back. Maybe if it goes through, can you look at that?

Mr CHAIR: Absolutely—that is a great point.

Rev M HALL: When my mum was at Rocky Ridge, I could not bring her back because she was under guardianship. That is the thing; if it maybe gets passed through the parliament, guardianship needs to be open more for people.

Mr CHAIR: Reverend, the same thing. My grandma, I used to look after her and then I left the country. I came back and she had become guardianship as well. I had the same fight and then I had to fight to get her care to try and help her. Guardianship, palliative care, medical care—all these things are very important. We know that they also interact with this. You cannot even—if a law gets made like this, it does not mean we can forget guardianship, palliative care and the health service. We know that there are those needs as well.

We can talk about that because what the parliament asked us to do is think about it together as a team. As Dheran pointed out, he is from a different party and Kat is from a different party and we are from a different party; we do not agree on everything, but we know this is a very hard issue and we want to work together and listen to people to try and fix problems, not make more problems. Guardianship is a very important one as well.

Can you tell me a bit more about palliative care and what palliative care is like at the moment?

Rev M HALL: Palliative care, just one in Katherine Hospital—there is (inaudible) building—in the Jack Roney Ward. In Darwin you have got the palliative care at the back of the hospital from the main place. We have been there and visited one of the families. We would like to see palliative care in our own community; we want it based here. Aged care, NDIS and all those health things, they all have different work departments. They have different job descriptions and that makes it complicated for us.

Mr CHAIR: It is complicated, yes.

The INTERPRETER: I think the most complicated part is when people are asked to sign applications, forms …

Mr CHAIR: Just say that again; we want to get that on the record. I am sorry; I missed it.

The INTERPRETER: The most complicated part is when a family member is asked to sign an application to identify that they are family for that person because when they call the hospital they say, ‘You will have to identify yourself if you are the child of this person to make their decision’. A lot of our families are like that. That is when they get upset, when they do not have the power to say yes or no for them to come home.

Mr CHAIR: Yes, we understand.

The INTERPRETER: As you heard from my grandmother’s sister, my great-grandmother had to pay her own fare to come home. That is a really difficult situation for us, and we do not want to go through that again.

Mr CHAIR: No, we understand that.

The INTERPRETER: We want easier access because we are not as rich as everybody else.

Rev M HALL: Another one I want to point out to you is about family pulling the plug, turning the machine off. We do not want that.

Mr CHAIR: This law, just so you understand, is not about pulling the plug. It has nothing to do with that. If somebody cannot—only you can pull out your own plug. That is what this is. Nobody can pull out a plug from you—no family member, nobody else can. If you are in a coma or if you have dementia and you cannot think anymore, this is not for you.

Rev M HALL: It goes back to the doctors, doesn't it?

The INTERPRETER: [Kriol spoken.]

Rev M HALL: Already they got my story, but maybe we can help others, you know, with their stories?

Mrs CARLSON: Can I just make …

The INTERPRETER: Sorry; I will explain myself again. [Kriol spoken.]

COMMUNITY MEMBER 3: Palliative care (inaudible).

The INTERPRETER: Palliative care is different to this—yes?

Mr CHAIR: It is different to this.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Healthcare is separate, palliative care is separate and VAD is separate. In the Northern Territory, of course, some doctors do multiple things, but this is different. You do not have to choose one or the other. If somebody is real sick, they can try to get treated first. If they are not recovering, they can go to palliative care and try to get better. That is it now.

Now, the question is whether there is one more option, for if people want. 'Palliative care will not work for me, and so me, my family, we decided I want to finish up better away from hospital', that is what VAD is about. Does that make sense?

[Multiple people speaking.]

Mrs CARLSON: What I am probably getting now from the room, I understand you have very strong culture and very strong faith. Maybe the words we are using here—which is voluntary assisted dying—are still very similar to what you are trying to achieve. You want the option still to come back to country to die. You may need assistance in just the travel part of getting you back. It could be something that we need to write in the report, that your interpretation of getting help to die is different to others who want the needle to stop the suffering earlier.

Mr CHAIR: That is a very good point.

The INTERPRETER: That is what I said to them in Kriol. I should have translated that in English. They would expect government to support them with transport bringing family home. They would not support government to inject their family.

Mr CHAIR: That is a very good point.

Mrs CARLSON: When you shared the stories about your grandparents, I went through the same with my grandmother who was very strong in faith. She had a dream about her grandmother calling her when she was asleep. We had to then take her back to her homeland and she died peacefully. I understand.

Rev M HALL: We know that. We do the same.

[Multiple people speaking.]

Mrs CARLSON: You still get the call.

The INTERPRETER: We are choosing that. What can you help us with to support that position?

Mrs CARLSON: I think you are still needing assistance, but not to the point where some people are going to need a needle to send them to sleep because of their pain and suffering threshold. Sometimes they do not have family, so they are by themselves; that is why they want this as well. They do not have children or their siblings next to them and they just feel they need to go sooner rather than later. The needle will help those people. But in your instance, you want to be around family. That is important.

The INTERPRETER: How would you bring our family home if we are making that decision to say no? What would you do to bring them home for us? How would you support us?

Mrs CARLSON: That is a good question.

Mr CHAIR: That is a good question.

The INTERPRETER: I asked that …

Mr CHAIR: I will give you a stab at it. At the moment, these words ‘voluntary assisted dying’ this is their model. We were asked to question this. We did not come up with this, but we will ask the questions. What I am hearing now, what Oly has just said and what you were asking as well, is that assistance to pass away might be broader than this report is thinking.

How could we help? There are many ways that it is possible for us to think about. The first and most important thing that keeps coming up over and again, is people do not want to pass in hospital. If they do not have to pass in hospital, they want to pass on country. We are hearing that loud and clear.

How could we help? There are other schemes already, like the patient travel schemes, and other measures to help medical transfers. It may be that we need to look at what we can do in that space. Maybe we need to do more effort in that space.

Mrs CARLSON: Adding to the report.

Mr CHAIR: That is right.

The INTERPRETER: What I understand now is that when family members are at the hospital and we ask for them to come home, they say (inaudible). If we want them home and finish here, we would expect them to be home urgently, and not just wait for the next bus next Tuesday because by the time next Tuesday comes, they will pass away in Darwin.

Mr CHAIR: I want to say one thing to Bobby’s point about how fast this is happening. Even if we write a report and give it back to parliament in September, then the government has to think about it and make a law. Then if the law passes—let us just say if it passed at the end of this year, it would still take 18 months, a year and a half, before any of this can be used. There is still a couple of years before anything will change or anything different will happen. But what we put in our report—because this is the report we were given and we wrote one report about this, then we wrote another report and now we will write a final report. In the final report …

Rev M HALL: Your draft report.

Mr CHAIR: Exactly.

In the final report, we can say more things about what the communities feel, what assistance to die might look like and we can also say that there is a very strong need for people to finish up on country; that is assistance for people.

The INTERPRETER: That is what they 100% want at the moment.

Mrs CARLSON: The other thing is all the other states have gone before us, so that is why there is a small advantage for us in the Territory to get it right, that the model fits the Territory too. If we know it will be different to the other states and territory, this is why it would be special to put these types of comments and ideas in this report to ensure your voices—how you want to be treated in your last few days.

COMMUNITY MEMBER 1: (inaudible).

Mr CHAIR: You will have to speak up.

COMMUNITY MEMBER 1: This word 'voluntary', that is the one you have got to use.

Mr CHAIR: Absolutely.

COMMUNITY MEMBER 1: Explain what it means, because us mob, you know, English we do not get—we have got no (inaudible) and what it really stands for. If I want to go to the (inaudible) and I volunteer myself for that, I will get a woman with (inaudible). This word here is a very important word. The explanation has got to be a simple one, so we can understand.

The INTERPRETER: [Kriol spoken].

COMMUNITY MEMBER 1: You explain the possible ways so we can clearly understand. We do not really understand English.

Rev M HALL: In the past years this thing was in the Territory because I remember the doctor …

Mr CHAIR: Thirty years ago, yes.

Rev M HALL: Thirty years ago. In the law we had in Darwin and they would bring it back when they come into politics—voting—it came back. I know about this problem because it happened years and years before …

Mr CHAIR: That is right—1995.

Rev M HALL: Then it was scrapped.

Mr CHAIR: Yes, that is right.

Rev M HALL: It got scrapped …

Mr KERLE: From Canberra.

Rev M HALL: Canberra, yes.

It is a new thing for some, but with us (inaudible) understand. That story about this voluntary thing, but it is a dangerous one in a way too; you know? Only one person—it was like he was God himself. The breath of life comes from the Lord himself, the holy spirit.

Mr CHAIR: For people who feel that way, they never have to choose VAD and that is fine. My father is a very religious man. He would not choose VAD, even if the law existed. But for some other people, we know they want that choice. That is what 'voluntary' means and that is what we have heard again.

Can I ask one other question of everybody in the room? I know lunch is coming and everybody wants to eat lunch, so we do not want to stay too long, but I have an important question at the moment.

When people are sick in Ngukurr, in this community, what are the options at the moment for them for finishing up? Who helps them here? Is it just family? Are there other support services? Do you have enough support? Is there anything?

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

The INTERPRETER: There are seven different languages in this community and it is a tribe too, like seven clans. It is not going to take one clan group to make a decision; it is going to take the whole clan to make that decision. That is how we …

COMMUNITY MEMBER 2: To make that agreement.

The INTERPRETER: That is our governance we have too, that we follow—our law as well. It takes time. We would need time and that is how we live—for that many years—and we have been living like that. We are used to that rule.

COMMUNITY MEMBER 2: Our law; our way.

The INTERPRETER: We still have it. I think that is what this mob, family, are deciding not to go forward with that, but still accept that law. We …

COMMUNITY MEMBER 2: We will work with that and try to make it better for us.

The INTERPRETER: [Kriol spoken.]

COMMUNITY MEMBER 2: [Kriol spoken.]

The INTERPRETER: Family is to come home and stay with us at home, surrounded by …

COMMUNITY MEMBER 2: [Kriol spoken.]

It is best that we try to work something out to bring our people back here.

Mr CHAIR: I agree.

COMMUNITY MEMBER 2: Our family, because with our mother—me and my older sister here—she had to pay all the fares back, and that is really sad. We do not want that for any family. We do not want our other families to lose another one south there, because we had to have teleconference last month, our uncle, where the doctor told us he was already dead, but the machine was keeping him alive. We do not want that; that is sad. If our family is very sick and cannot pull through in about a month or a year, bring them back home.

Mr CHAIR: At the heart of this, the reason people wrote this is also for compassion. That is the thing; people wrote this because they do not want the person who is sick to be suffering, but also we know the people around them, if there are people around them, they also suffer. We are trying to figure out how to reduce suffering. Making this law is about reducing suffering. That could be different for different people. For some people it might be getting a needle so that they can end their suffering. For other people it might be about making sure that we can help them come back to country …

COMMUNITY MEMBER 2: And making it comfortable for both, with the family.

Mr CHAIR: Absolutely, yes.

COMMUNITY MEMBER 2: Providing financial ways, comfortable accommodation and food for the relations who are looking after the deceased—the person who is passing away.

Mr CHAIR: Sometimes what the hospital or the health system here will think is when somebody is too sick in the hospital, they will say, ‘We do not want them to suffer and that is why we will not let them travel’.

COMMUNITY MEMBER 2: Yes, but that is not in our culture.

Mr CHAIR: No, we understand.

COMMUNITY MEMBER 2: We do not say that. We just ask them to (inaudible) for that person. We want to look after our family.

Rev 1: I think the word ‘suffering’ is the wrong answer, because it is not right.

COMMUNITY MEMBER 2: It is not in our culture.

The INTERPRETER: [Kriol spoken.]

Rev 1: (inaudible).

The INTERPRETER: [Kriol spoken.]

COMMUNITY MEMBER 2: [Kriol spoken.]

How did she come home? Taxi. She had to pay her own fare; we did not pay it for her. The Health department did not pay for it. No government, no financial ways for her to come home. (Inaudible) taxi price. She got her pension money and she did not have enough, so she asked some family for most of that. We chucked in for her to come back (inaudible) and then floodwater (inaudible).

The INTERPRETER: During the flood?

COMMUNITY MEMBER 2: During the flood. That is the sort of thing (inaudible) mum coming back by herself, her own way.

COMMUNITY MEMBER 5: Before that bridge and everything was there.

COMMUNITY MEMBER 2: Before that bridge and everything. This was 10, 20 years ago.

The INTERPRETER: Even with the bridge it still floods there.

Rev M HALL: We have a system—Angel Flight and CareFlight. Maybe put something there to support more. CareFlight can bring the patient back, or Angel Flight—something like that for coming home, for support.

[Multiple people speaking.]

Mr CHAIR: Wrapping these thoughts up, a very important thing here, your …

The INTERPRETER: Mother.

Mr CHAIR: Brother, sorry …

The INTERPRETER: Mum.

Mr CHAIR: No, behind him, holding white paper. You, sir …

[Multiple people speaking.]

Mr CHAIR: Robin, I am sorry; I did not get your name before.

[Multiple people speaking.]

Mr CHAIR: I know who you are; I just did not hear your name before.

Robin, I wanted to say what was really useful in what you said—which is the same point in many ways that we are all making—is the definition is very important. What a word means is very important. Not everybody understands ‘voluntary’ means choice, people to choose.

It is the same thing when we are talking about assistance. ‘Assistance’ in this document means a very narrow thing, but we are hearing from all of you that assistance to die well might involve a lot more. It might mean, for example, using some of the things we already have, like CareFlight, Angel Flight, palliative care services, to broaden those things like patient travel schemes. They might all be part of what we can report back and say, ‘People in remote communities, or people in this community, said to us that they want more assistance to be able to die, when the time comes, around their family—in a more compassionate way, surrounded by family.’

This is why we are here—because we have had many conversations and written many words already, but this is the first time today that we have had this conversation with you guys. I feel like I am learning a lot and I think my colleagues feel the same way.

COMMUNITY MEMBER 1: (inaudible) just about half the Ngukurr community do not understand.

Mr CHAIR: Yes, we understand that.

[Multiple people speaking.]

COMMUNITY MEMBER 1: [Kriol spoken.] Voluntary—you have got to explain in simple English. You will not say voluntary; you will say (inaudible)—‘help you through this thing’, not ‘voluntary.

Mr CHAIR: We will think about the words better, but really what we are hearing is ‘choosing or helping how you finish up’.

COMMUNITY MEMBER 1: That is the one.

COMMUNITY MEMBER 2: The report there, somebody from the Language Centre can write that report in Kriol for us to read.

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

The INTERPRETER: I will explain that. [Kriol spoken.] There are three people too, in our culture, that make the decision for a person’s life.

Mr CHAIR: Yes, we understand.

[Multiple people speaking.]

Mr CHAIR: Hold that thought for one second. I want to finish this up.

Could you translate that back for us in terms of you also have a system for three decision-makers. Could you just explain that for us?

[Multiple people speaking.]

The INTERPRETER: I will go with three, because everybody knows the three important ones.

COMMUNITY MEMBER 1: Authority and a system—authority.

Mr CHAIR: Okay.

[Multiple people speaking.]

COMMUNITY MEMBER 1: Authority is the big thing, and a system (inaudible).

The INTERPRETER: What I was saying is I am not going to compare the two different cultures …

Mr CHAIR: No, just to explain things.

The INTERPRETER: I will explain. The three people who are important who make decisions in everything we do in community are called *jungai*. How would you explain a *jungai*?

COMMUNITY MEMBER 1: Custodian.

The INTERPRETER: (Inaudible) is the traditional owners. (Inaudible) is the head person, the person who makes the last decision.

Mr CHAIR: Like a chief?

The INTERPRETER: Your grandmother, your mum’s mother.

For us, that is why they say no because they have to go through that system. It is not one person’s decision, but three. They are not only three people; there is like 10 people, and they have to go through that system.

Mr CHAIR: That is very helpful. We want to get that on the record.

The INTERPRETER: Yes, you might think it is an easy road, but it is not; it is a very …

Mrs CARLSON: You still making decisions along the way, which is similar to …

The INTERPRETER: Similar to this one.

Mr CHAIR: We are trying to get on the record that there is a decision-making structure to pay attention to.

K McNAMARA: There is a question the Chair asked that I think it would be good to get an answer to. We hear you say no and we say okay; ‘Ngukurr says no’, we tell the government. But if a lot of other people say yes and maybe the government makes this law, if other people use VAD how do you feel about that? Does that upset you or worry you?

COMMUNITY MEMBER 2: We will have to work on how we can …

[Multiple people speaking.]

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

K McNAMARA: I was just asking if you say no and Ngukurr says no, but if lots of other people say yes, if maybe the government brings in the law and other people want to use VAD, how would you feel? Would that worry you?

Mr KERLE: No-one is making you use it. It is voluntary.

The INTERPRETER: [Kriol spoken.]

COMMUNITY MEMBER 4: We still use our governing law—our law. It is still the same. That is what we are going to follow. If other states want to do it, we do it in a different way.

K McNAMARA: So, you do not mind …

Rev M HALL: If they say yes—you have got maybe 21 communities—and then one says no, what will happen then?

The INTERPRETER: [Kriol spoken.]

Rev M HALL: The majority group is 21 and then automatically bounce back to us because we are the ones who said no. Do you know what I am getting at?

Mr CHAIR: I know what you are getting at. What we know already from people who have been thinking about VAD for a long time is that the majority of people in the Northern Territory that have been asked before want some law and some option, but exactly what that looks like we are not sure.

We also know that most of those times, they have not asked people in community. We are not here to make a decision on the final answer. We are here to write a report back to the government and parliament for the whole parliament to consider.

Rev M HALL: In the Territory?

Mr CHAIR: In the Territory. This is the Territory.

The INTERPRETER: No more federal—they already got it.

Mr CHAIR: That is right. Every other state and territory, they already have a plan. A really important part in this thing is that all of them say that if we make a law for this in the Territory, it cannot be the same as the law for South Australia or Queensland or ACT.

Unidentified Speaker: No. It has to be a law for the Territory.

Unidentified Speaker: The community.

Mr CHAIR: That is right; it has to be right for us. That is why this is our chance to learn from you what we could do to make it easier for people to pass.

We realise that this is a very narrow definition, a very narrow explanation, of what is voluntary assisted dying. We did not pick these words; these are the words we got. Straightaway when I said ‘choice’ and ‘help to finish up’, everyone was like, ‘Okay. That makes a lot more sense to me.’

We will talk more. You asked us how many communities we have been to. Today is the first time we are here. We are doing this all month. We will go to maybe a dozen communities if we are lucky. We will talk to people about choice and help to finish up. What kind of choice would you like as a community? What kind of help would you like as a community? What support would you like so that you can finish up better?

Speaking of time, everyone, lunchtime is pretty close to coming.

I want to first of all say thank you to everybody for coming, for staying, for sharing with us. It is very important. We have learnt a lot today. I have learnt a lot. I think all of us have learnt a lot.

Before I close everything up, is there anything that my other committee members or anyone want to add?

The INTERPRETER: What is the next step?

COMMUNITY MEMBER 1: Why are you wanting?

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

COMMUNITY MEMBER 2: What we want—like a consent thing.

The INTERPRETER: The consent form—we will do a translation.

COMMUNITY MEMBER 2: Yes. Translate the whole thing.

[Multiple people speaking.]

COMMUNITY MEMBER 2: On behalf of my people in the church, I just want to say no, we do not want the VAD.

The INTERPRETER: Yes, they understand. [Kriol spoken.]

[Multiple people speaking.]

The INTERPRETER: Listen up, please. [Kriol spoken.]

Mr CHAIR: The answer to Robin’s question is anything that does happen, if it finally happens, we will make sure that it gets translated into the languages so people can understand—so in Kriol here.

The INTERPRETER: Everything—even if they said no or yes, things need to be translated.

Mr CHAIR: We will record for our records that there is significant community interest in seeing what we say at the end, which means that we have to spend some time translating the big documents at the end as well—is what will happen. That will take some time and that is going to happen in the future.

I want to say again that we have not made decisions. We have made no decisions; we are here to learn from you about how we can move forward …

COMMUNITY MEMBER 4: We are sharing information.

Mr CHAIR: That is right; sharing, and it is two-way sharing.

Mr KERLE: It is really important because we did not know about all the other issues around CareFlight and coming home to country from the hospital. We did not know about that.

The INTERPRETER: [Kriol spoken].

Rev M HALL: Last one—not for the health side, but it is about the food. Everybody, some will be served at the office.

Mr CHAIR: Okay.

The INTERPRETER: [Kriol spoken.]

Rev M HALL: [Kriol spoken.]

Mr CHAIR: That is a good time to break for lunch.

[Multiple people speaking.]

Rev M HALL: Thank you, all the government people. Through Caroline, it was short notice—sorry; I did not apologise—I was talking with her and the bishop. The bishop organised from the diocese for me and my husband to do this.

Mr CHAIR: You have done a great job. This has been very good for everyone. We are very grateful to Caroline and Katie …

Rev M HALL: I am saying sorry …

K McNAMARA: We apologise for not enough time.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Everybody is apologising.

[A prayer was read.]

Mr CHAIR: Thank you very much.

The committee suspended.

Community Consultation Drop-in Session

Mr CHAIR: We will start by introducing everyone, and then I will tell you more about what we would like to talk to you about. My name is Tanzil, I am one of the members of parliament here—one of the five us that are members of parliament. We also have three staff people here from the parliament who have come to help us.

We have come here today to talk with you, to hear what you have to say, to try to learn from you, basically, on the stuff that we are looking to discuss.

I am the Chair of this committee. We have five of us on this committee. This committee's work is about legal and constitutional affairs—law, basically. We were asked by the government to look into this report. A year ago, this report was written. We did not write it. Doctors, lawyers, healthcare workers and a lot of people were consulted. This report is basically about how to give people choice to finish up better and it is called Report into Voluntary Assisted Dying. What we want to know is a bit about what you think about voluntary assisted dying.

Let us go around the room first and introduce each other.

Mr YOUNG: Hello, my name is Dheran Young. I am a Yaegl person from New South Wales, but I am also the Member for Daly. I am a member of parliament for the Daly Region which takes in Berry Springs, Wagait Beach, Dundee, Daly River, Wadeye, Peppimenarti, Palumpa and all the homelands around there. Similar to your local member, Selena Uibo; I am the same as her, but on the western side of the highway.

K McNAMARA: My name is Kat McNamara. I am also a member of parliament. We are all from different parties. Some of us are in the same party and some different. I am the Member for Nightcliff, so I am in the city and member for there. I am with the Greens party and this is a committee that has different parties on it.

Mr YOUNG: There are different groups working together. I am with the Labor Party, the same as Selena.

Mrs CARLSON: My name is Oly Carlson. I am a member of parliament as well. My suburbs are Leanyer, Wanguri and Muirhead, next door to the main hospital and Casuarina. I look after all those people. I am a member of the Country Liberal Party, and I was born in Darwin, a long time ago, so I am a Territorian.

Mr KERLE: My name is Matthew Kerle. I am another member of parliament on the committee. I represent Blain, which takes in parts of Palmerston. I look after Moulden and Woodroffe. A lot of people that come in from community stay in Moulden; that is my area I look after. I grew up around Batchelor, in that area. I am also a member of the Country Liberal Party (CLP). I am here to listen and hear what you have to say.

[Multiple people speaking.]

Mr CHAIR: That is the problem. You only see us at voting time. That is why we want to come down and hear what you have to say now about …

Unidentified speaker: I think they see Selena quite often.

Ms JOSHUA: Thank you for coming in. We are happy to listen. It has been a while, talking about what happened there. It has been ups and downs for our people in and out of hospital, and it is very hard for the people here in Ngukurr.

Mr CHAIR: Let me start by saying a few introductory …

Mr KERLE: Sorry; we introduced ourselves, but is it possible for you guys to introduce yourselves so that we know. My understanding is that you are a traditional owner, so there is respect there. Is that okay?

Ms JOSHUA: To the Robertson, Conto and Roper family, yes.

I am Tanya Joshua. My job is customer service. I do the mail for the community. I have been here for a long time now. I spent like 12 years working with Centrelink and then moved on to the post. I am still here helping the girls here.

The INTERPRETER: She is one of our members for our local authority.

Ms JOSHUA: I am a member for local authority as well. This is our room. This is where we discuss about the community and what we need for the young people and old people in the community, and meet more (inaudible) everyone what they need.

Mr CHAIR: We are in the right room then, definitely.

Ms GEORGE: I am Margaret George. I am one of the (inaudible).

Mr CHAIR: What about you guys?

ROBERTA: I work with Margaret, so we are both in the same area. I am Roberta.

Mr CHAIR: Nice to meet you, Roberta.

MARITA: I am Marita. I work as the receptionist.

The INTERPRETER: I am the interpreter.

Mr CHAIR: Also hiding in the background we have?

Ms HELME: I am Katie Helme, committee secretary.

Ms EAGLETON: I am Georgia. Katie is my manager. I do research for (inaudible).

Ms WILLIAMS: I am Caroline. I support the committee at parliament.

Mr CHAIR: Caroline is everyone’s boss.

The INTERPRETER: No wonder she is quiet.

Mr CHAIR: It is good to know who is in the room. I am glad we did that.

The main reason we are here today is to talk about something that is difficult, which is voluntary assisted dying. We did not come up with that name; that is the words that are used around Australia to describe giving people choices to help finish up better. That is basically what this is about. For some people that means when they are terminally ill, suffering, definitely going to die, that provides them the option to be able to be surrounded by people they care about, or in a place they want to be instead, for their life to end without them having to suffer forever and ever.

The rest of Australia—every other state and territory in Australia—has a law for voluntary assisted dying (VAD). The Northern Territory is the only place that does not have a law for this. As you pointed out, the Northern Territory did have a law for this back in 1995.

In 1995 we had a law, then the federal government decided that the law was no good and they struck it off. Twenty-five years later, in 2022, they decided that now we could have these laws again, so now the discussion is happening: should we have a VAD law in the Northern Territory and, if we have one, how do we make it the right one so that it is right for the Northern Territory—not the same one as South Australia, Queensland, WA or whatever it might be?

Before I say anything else, this is a difficult subject to talk about; we know that. If anybody is upset or wants time and needs a breather, let us know; we can always stop. We are talking about death and dying and how to make it better for people, more caring and more compassionate. What we do not want is people suffering.

For some people—we heard in the last session as well—suffering means being stuck in the hospital, not being able to come back to country. For other people in the cities, sometimes suffering means they cannot take any more pain and now they want an injection—after doctors have said yes, they can have it—to be able to end their suffering.

The most important word in this is ‘voluntary’—voluntary, choice. Nobody is forced to do anything. Our job—the five of us who are here, helped by these three—is we have been asked to look at this report and say, ‘Is this report any good? Does this report work for the Northern Territory? How could we make the things in this report better?’

One of the things we know that did not happen in this report is not enough remote communities and Indigenous people were asked, ‘What do you think?’ That is the first thing on our job list.

We have written our own reports about this to talk to other people. I invite people to give us information and submissions. We want to know what you think because remote communities have not said a lot in this space.

In the last session, people talked about palliative care, healthcare services, CareFlight—all these things are relevant. If you have any thoughts about any of those things—Centrelink is also important. I also worked for Centrelink, by the way, for a long time—side hustle. The point is that we want to know what people in Ngukurr feel about this. How is the healthcare system going? Are people able to finish up on country? Are there problems with people coming back from the hospital? Also, if there was a law like this, how do you feel about it? Whether you use it or not, is it okay for you if it happens or would you rather it did not happen?

We have many questions, but we mostly want to hear what you have to say. We want to hear your stories or if you have thoughts about this. Let us start by hearing what you have to say initially about this. Any of you guys.

Ms JOSHUA: Last time we had one of the family came in from Darwin because they could not have him there now. They just sent him back here with us. We only had him for three weeks. When it was the time for him to go, he just passed away in my living room.

Anyway [Kriol spoken]. Noel Thompson is my husband’s stepfather. When the doctor sent him back, he stayed here for a little while. He made that choice in Darwin, ‘I will go back to my son’s house and I want to pass away there’. That was his decision to make. When he passed away there, other family was shocked.

They did not know. They think that we poisoned him or whatever, but it was not; everybody started pointing finger to my husband that he did something. But after a while, we have to settle that mob and tell them that it did not go that way. It was himself making that choice. He did not concern anybody but his son, Gary Thompson. That is the decision. This is the kind of thing that when there is family or a loved one in hospital now, it is okay to make that decision there, for letting the family know, but we need to let other family know as well to continue what they wanted to do. That is all I can say. That was the last time I remember.

Another one, I lost my mum. She was in Rocky Ridge. I did not see my mum. They just rang me and told me that she passed away. Rocky Ridge is the last aged care when people move on from Kalano aged care. You have Red Gum and then you have Rocky Ridge. Rocky Ridge is the last one where that person is unable to get up and walk around. That is the last choice that they will be in for aged care. Just to warn other families.

In the end, Aboriginal people love to have their mum or dad come home and pass away in their house, which is what happened with Noel Thompson. People can make that choice.

Mr CHAIR: Do enough people get the choice to be able to come back here to finish up?

Ms JOSHUA: Yes. That is what I …

ROBERTA: Most family members.

Ms JOSHUA: They can. Yes.

ROBERTA: It is up to the patient who wants to come home to be with their family. He tells the doctor to come home then the family agrees and we keep them at home.

The INTERPRETER: [Kriol spoken.]

ROBERTA: That is what we have been doing for the last couple of years, they have been sending families back home and finish off, but sometimes when the patient is really weak and (inaudible) if that call does not go right, we cannot make it back home. Yes, we understand all that thing. That thing has been happening all along and if not this year, everywhere else. We know the system. But for this it is difficult to understand what we are saying with the injection, yes.

The INTERPRETER: [Kriol spoken.]

ROBERTA: None of them understand.

The INTERPRETER: [Kriol spoken.]

[Multiple people speaking.]

Mr CHAIR: So you three all understand the system pretty well already anyway. The healthcare system is obviously trying to help people when they are sick. When the healthcare system cannot help any further, we go to the palliative care system, which is the last thing to try and help people when they are dying. That is the last step.

We were asking before about palliative care here. Is there enough? What could be done more? What already happens at the moment?

Voluntary assisted dying (VAD) offers another option as well. If palliative care is not helping somebody to finish up well and if a person who is dying goes to a doctor and says, ‘I would like VAD’, and the doctor says, ‘Yes, you are definitely dying in less than a year and you still have sense, you can give consent’. If that person gives consent, they check as well with a second doctor. If the second doctor also says yes, then somebody can ask with a doctor and a nurse’s help for an injection to finish their life.

We know many people do not want to use this, but we also know many people do want to use this. The question is: should we allow people to have a choice or do we just not have a law for this? Every other part of Australia has a law for this and there are many people who believe the Northern Territory should have a law for this as well. We know some people will never use this.

I was saying before in the other session, my dad is a very religious man. He is not going to use VAD if VAD ever happens. He believes that he just has to pass when he passes, but other people believe that they should have the choice if they are really suffering and really dying and nothing can be done to help them, 'Why cannot the doctor help me to stop suffering?'

We want to know whether or not you would be happy or unhappy or have any real problem if other people also have choice. That is an important question because nobody has really asked people in communities these questions enough. We would like to know what you think.

The INTERPRETER: [Kriol spoken.]

ROBERTA: It is not for me. I do not want that. I would not accept that.

Mr CHAIR: You do not want it in the community, I understand? What about if the rest of the Northern Territory had it? Would that make you unhappy, happy?

ROBERTA: Unhappy.

Mr CHAIR: Unhappy, okay. We know from this report and other things that maybe 75%, three-quarters, of the people in the Northern Territory keep asking to say that they would like us to make a law like this, but they want it to be safe and a choice. Do you think, even knowing 75% of the people want it, we still should not have a law?

ROBERTA: It is up to the people to say.

Mr CHAIR: Yes, sure.

Unidentified speaker: It is really …

Mr CHAIR: No, but we are interested in what you think as well.

The INTERPRETER: [Kriol spoken.]

ROBERTA: My answer would be the same and I would say no.

Mrs CARLSON: If the law still went through so that those who want to use it have the option to use it, but even if it was law, you would still make your own choice that you would never use it, would you; is that what you are saying? Is it still okay then to have the law and then you would never need to use it? Is that something you would not need to use? Are you okay with the law still going ahead for other people who want to use it?

Ms GEORGE: Yes, if they want to keep with the law …

The INTERPRETER: [Kriol spoken.]

ROBERTA: You would not say yes from the hospital. They are not well.

The INTERPRETER: [Kriol spoken.]

Mrs CARLSON: We talked about this; about consent too. They must still be of sound mind so they must still be able to make that decision themselves. For people like yourselves in community, we understand now from this morning's talk in the church that you still consult with your family members to come to a consent, an agreement of yes or no.

We are not taking your choice away to still talk to your family members and you still get a choice to full consent. You still have to make consent. The doctor does not come and make the decision for you. Once you have consented, you then have to ask the doctor, 'Am I still eligible to go down this path?'

The INTERPRETER: [Kriol spoken.]

Ms GEORGE: Because you are ready to make that choice, so there are two ways in this, yes.

The INTERPRETER: [Kriol spoken.] It depends on the person. [Kriol spoken.]

[Multiple people speaking.]

Ms JOSHUA: he law is there; it is going to be strong in the Northern Territory. Whatever decision-making, it is all up to the family and it stays that way.

ROBERTA: That is what I was saying.

Ms JOSHUA: We all know each other in the hospital, to the doctors, to the community here. My choice is that yes, we have a law that works and stays there always, along as everyone is happy in our community and no matter where they live.

The INTERPRETER: [Kriol spoken].

Ms JOSHUA: Because the government will forward it to these people here, when they are in charge of the voting.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: That is very important, the writing to give consent. That is one of the things that this report says, that nothing can happen even if you go down this path unless people write to give consent. We want to make sure that is the standard.

Some people say, ‘No. You do not need written consent because literacy and numeracy is not as high. It should just be verbal consent.’ We want to know whether people think that is okay or whether written consent is definitely something that is required for these things.

The INTERPRETER: The written thing is the cultural part when people make decisions. The three things that we mentioned at the church, that used to be on paper. The consent should be verbal.

Unidentified speaker: Both ways done. Make it both ways so that they can understand too, by seeing it not just by saying it.

The INTERPRETER: That is why Robin was asking for this to be translated. A lot of people here cannot speak English and I am only one interpreter. I would prefer verbal consent and, as an interpreter, it would be there.

Mr KERLE: Can I rephrase what you just said to make sure I understood? If this went ahead, there should be something in there that says if the person is an Indigenous person who lives according to culture, then the laws need to have regard to the cultural decision-making as part of accessing the VAD. If it is somebody in Darwin and they are not a person who lives according to culture, then they do the writing and give their consent and see the two doctors. But if the person is an Aboriginal person who lives according to culture, then they should have regard—before the doctors say yes and all the other stuff—to the cultural decision-making. Is that right?

The INTERPRETER: Yes. It always feels like one-way street decision-making and not like a family. It is always in a family, decision-making in communities and (inaudible) people, especially in Ngukurr. Other communities have other things; they are different, even though we have the same traditions. There is different cultural practice.

[Multiple people speaking.]

Ms JOSHUA: Can I explain something? One of the things that I cannot get off my mind because I lost a granddaughter last year, had an accident in Palmerston where (inaudible) is.

Mr KERLE: Whereabouts?

Ms JOSHUA: I lost a granddaughter in Palmerston. She got hit. She was in hospital. The hospital let me know there was an accident, but I was at a call at 11 o’clock, some family telling me from Darwin that her sister passed away. I rang Darwin at 11—probably quarter to 11 or half past 12—‘I am just chasing up on my granddaughter. Was she in the Cowdy Ward now?’ ‘No. We do not know anything.’ How could that be? We tried calling Palmerston, but no-one got an answer there. No response. I waited awhile and the nurse said, ‘I will give you a call’. She kept calling me back every five or 10 minutes. The last she was calling said, ‘Yes. She is here. She has just come in. She is still breathing.’

Half an hour the next day, I rang again at eight or nine o'clock in the morning, the sister explained to me, 'Since we put the machine and everything on her, she started breathing slowly'. Because of the pressure in her head, it was deep and all the skull inside and the brain, they had to—it was like 50/50 chance. It did not last long. I was really upset about it after that. The mother and we all went into Katherine, but I missed the bus. I called the doctor, 'I will be coming in. I just missed the bus at four o'clock. Can you wait for me until I get there tomorrow?' But because the mother, my daughter, my sister's daughter, as soon as she went there she was the other family's relative from Ngukurr, but they were the wrong mob. So it does not matter—when someone is injured in a hit-and-run or whatever wherever the accident is, you have got to give time. As soon as I heard on Tuesday at 10 o'clock, they called (inaudible) I was devastated.

I did not even rush to come in there to see her because I believe. I have got faith, I believe in God and he shows me and I wanted to touch his head to heal it, because you have to give me time for the pressure to go down. From the doctors you have got to find out first what will happen to this person instead of just rushing in and pulling it out. She was miscarriage, I found out, and now there is a court tomorrow out at our camp for the driver. I am just looking at the clinic, what happened there at that time.

If somebody in an emergency or whatever there, give time—give maybe two or three months—until everyone goes and see her. Once everyone is satisfied to see the person in the hospital, then they can pull the tube out or the police can find out what really happened, who was around. Because I remember seeing these things in the movies. There was a movie where they kept somebody, you know—as I was thinking about my granddaughter. It is really hard. I still have that loss. (inaudible) the victim paper I am going to send it back to the police officer later or maybe tomorrow morning.

That is the thing that is really hard for me. How can we get to that if a person is in a coma? Is there a way we can give time for family to visit them, last thing, or friends or whatever that he had? This is one that I missed last year. (inaudible) I was really upset at Mataranka and (inaudible) family on the bus, nobody talked to me. I sat angry because I did not have the chance to see my granddaughter.

That is why sometimes I feel quite—you know—cannot hold back. That is the arrangement that the government can make a choice as well, that any family that passes away in the Northern Territory if we can make a decision, give them time, give family and everyone to go and see them for the last time. That is the thing, I just want to say here, it is really sad.

(Inaudible) next door to my daughter (inaudible) there is a photo of her, she is so beautiful, just the thought of her. I sit down and talk to you, 'Hello, granddaughter, I am missing you. I wish you were here.' Sometimes I just talk to them and then go back home next door.

Everyone in my family, they are missing someone, even though I lost my elder sister back in 2023, I never had a chance to go and see her up in Darwin as well. Anyway, pretty sorry to bring this up, but.

Mr CHAIR: No, it is all relevant, and we appreciate you bringing it up.

Ms JOSHUA: If a doctor can just say for, it does not matter whose family is in there hit-and-run, and least give them a chance to live or stay there because she was still alive, breathing slowly, she could hear everyone talking because my granddaughter (inaudible) told me, 'Nanna, I am talking to sister and she is listening. Every time I talk to her the tears run down.' When she mentioned that (inaudible) she reminded me that my father was in ICU and my aunty went over there and my cousin said the same thing, 'I was talking to Uncle and I could see the tears'.

When you see the tears on someone, just an example, because now you are saying it you are going to get the idea of what I am saying. It could be anybody lying at ICU and someone sit down and talking, but he is there because the doctor has not pulled the tube out because the person is still breathing. That makes sense. That is the thing that I hold inside of myself about my father when he was there and now my sister's granddaughter.

Mr CHAIR: Our job is not to make a law; our job is to write a report. Everything you are saying will help us in what we write.

Ms JOSHUA: Yes, I know, but in Aboriginal people it is really hard.

Mr CHAIR: Absolutely.

Ms JOSHUA: I know no-one who had to do that, but to me it is a bit difficult for other families. That is all I am saying.

Mr CHAIR: This law that they are talking about is to try to be more compassionate. We know that what you are describing is a different type of compassion that is required as well. Whether it is with regard to palliative care or end-of-life support as you were just talking about, these are all things that we can think about and reflect on.

It is quite clear we hear now in different forms that the communication between Darwin and RDH and the healthcare system and out in communities is not always perfect and it could be better. That is the kind of thing that we can make sure we include in what we talk about in our report as well. All the doctors are obviously trying to do the best they can as well, but it helps for us to have these conversations and think about these things together once in a while so maybe we can try to improve some systems.

I wanted to see if you guys have any thoughts. Sorry, yes, go ahead.

ROBERTA: There are two ways for concern that people are going to get a needle (inaudible), but there are also people who maybe—what you mob understand, doctors have different drugs too. When you have cancer and you are dying in a bed, they give you one medicine (inaudible). They numb you; you cannot feel any pain. [Kriol spoken.] I experienced that because my mum passed away in 2009. She was also an Aboriginal health worker and she knows every drug. While even suffering, she knew all those medicines and said, ‘No, I do not want that; I only want this, and give me what I am asking, this medicine.’ I thought about that. [redacted]

The INTERPRETER: [Kriol spoken].

ROBERTA: Yes, you can feel that pain. They give it to you in a white tablet. You put it underneath your tongue and then it stop in a couple of hours and then you sink and if you want some after that, if that thing did not work, they give you another little thing in plastic …

The INTERPRETER: Panadol?

ROBERTA: No. I forgot the name …

Mr CHAIR: No. She is talking about pain-relieving medications like epidurals …

ROBERTA: Yes, like that. What you do is numb your body and you cannot feel any pain. You (inaudible).

Ms WILLIAMS: Epidural, you know, when you are pregnant and you are birthing. Epidural, yes.

ROBERTA: That is …

Mrs CARLSON: It goes into the spine to stop the nerves.

The INTERPRETER: Pain relief.

ROBERTA: No, not that.

Mr CHAIR: They are the same kind of things. What we are discussing are pain-relieving medications. Some of them are very strong like the ones you are describing …

ROBERTA: This was a drug that mum told me that she had chosen which one, but I have forgotten the name of it, description of the thing. I know which one I am talking about. You are probably talking about the other relief, yes. This drug is different from the others. It helps people.

The INTERPRETER: Is there any other drug that is stronger than that?

ROBERTA: Yes, you can ask your doctor.

Mr CHAIR: There are many other types. Epidurals that people have, commonly in labour is like one stem, and then there will be higher-level painkillers that can cause even more pain relief and then there are even higher ones that can actually help people.

Unidentified speaker: Like ketamine and …

Mr CHAIR: The highest levels of these kinds of things are these drugs.

The INTERPRETER: (inaudible).

Mr KERLE: It might be because her mum needed …

ROBERTA: My mum was a nurse and she …

Mr KERLE: You mean like a high dose of painkiller?

ROBERTA: Yes, and different from that.

Mr CHAIR: A dose of something like morphine at this level will cause pain to go away. A dose of morphine at this level will cause someone's heart to stop and for them to actually pass.

Unidentified speaker: Yes, if someone has a cancer but a different thing—'I do not want that. I want this'. I am getting to that stage where the pain I have more and more. (inaudible) ask the nurse for an opinion and died peacefully, no pain.

Mr CHAIR: That happens all the time. What you just described; you are 100% right. Thirty years ago when they were doing the 1995 law I remember at that time it was widely known and reported as well. Doctors will tell you that when somebody is suffering, really in pain, sometimes they will give them painkillers that are so high …

The INTERPRETER: This was in 2009.

Mr CHAIR: It happens every day now, but the difference is that right now it is not legal. It is not actually legal to give somebody to give painkillers that are so high that they will cause somebody to pass on, whereas if a law like this existed it will allow people to be able to choose that. It will allow a doctor to also be able to help without having to pretend that they are doing that help.

The INTERPRETER: So what I am getting from everything you said, my grandmother, she is saying it was illegal for the doctor to give her mum that medication.

Mr CHAIR: Yes.

[Multiple people speaking.]

ROBERTA: She was a nurse herself. She knew all the drugs that were given—'I do not want this. I know which one.'

Unidentified speaker: (inaudible).

ROBERTA: Yes, and he knew about the nurse stuff (inaudible).

Mr CHAIR: So what you are describing is essentially this. The difference with this is that now we are trying not to hide it and make it open. That is the difference. Right now maybe if you have one doctor who is sympathetic then they help somebody to finish up and pass on with no pain, but there is a risk for the doctor because at the moment it is not part of the law to allow people to do that.

K McNAMARA: I think it is important to say that with this idea for a new law it is not just any doctor. The person has to go and say, 'I want this', and they speak to one doctor and then they speak to a second doctor. This will be very separate. You have a normal hospital and then only if you are dying and very sick then you ask, 'Can I go and get VAD?' and that is separate from hospital.

Mr YOUNG: Also it will be more likely if you do say yes, you want VAD, you also have a choice still. After making that decision you can say, 'I do not want this'. You can change your mind. Once you make that decision it does not mean it is going to happen. I think in other states people change their minds. People say yes, and then only 20% of people who say yes actually then take it—roughly.

The INTERPRETER: You have your choice.

Mr YOUNG: You always have a choice up until …

The INTERPRETER: [Kriol spoken.]

Mr YOUNG: It is choice, yes.

The INTERPRETER: If that person is here, is that medication going to be in the clinics? Where is the doctor going to be? How would they put in …

Mr CHAIR: Good question. The answer at the moment, in this report, is that because only a small number of people actually use this in the other states and territories, a few hundred in each state. If we think how many people in the Northern Territory this might apply to, it is probably less than 100, maybe less than 20 people every year—if it even happened.

For that reason, because these are dangerous medications, dangerous drugs we are talking about, we would not keep them in communities. We would not keep them in small hospitals; we would only keep them in big hospitals in the city. Then, if somebody needed it—for example, in a community. Let us just say in a community somebody decided they want this help to finish up. They spoke to a doctor and the doctor said, 'Yes, we want to help you'. They spoke to their family and community and the family and community also said, 'Yes, this is okay'. If this was to happen, then probably doctors and nurses would come down from Darwin—if you like, a remote team—and help somebody finish up on country. The drugs are never going to be in the community, except when they are brought down to be used. That is how it will work.

The INTERPRETER: That is really important question because a lot of people think we have a lot of the medication at our clinics. It is a good question and also a dangerous one too.

Mr CHAIR: That is right. There is no chance …

The INTERPRETER: I should have asked that …

Mr CHAIR: That is okay, we will cover a lot of this as we go.

ROBERTA: Because the drugs, when they have a strong one, they do not put it there; they keep it away. Only consent by the doctor …

Mr CHAIR: That is right.

ROBERTA: … and the family would remember to tell the doctor. That is if he said yes.

The INTERPRETER: [Kriol spoken.]

Ms JOSHUA: Another one I want to explain is about my sister. Speaking of that, that people say that you would make a choice, I was speaking when my sister passed away in 2023 in Darwin hospital in February. That night she was talking to me really strongly, in the evening. Somehow, they explained to me that a few doctors and nurse going to explain to you in another room. When I go back and they explained to me, some of the nurses went into that room, it was really strange. They did not ask or explain properly.

I did not get the referral from my sister giving them permission to (inaudible) sister. So when that happened in that room I can hear quiet, like something was not right. Whatever the decision they were making, they were making for themselves. One of them mentioned, 'Oh, your sister going to pass away soon, any time'. No, they were just getting something from me, giving that feedback to them and giving permission about certain things.

Somehow, I am starting to remember, but I was not remembering there, but I forgot about it, then later. Then the next day when her daughter (inaudible) rang, 'Mum passed away'. I do not know what really happened that night because they were starting giving her antibiotics, something like that. Why are you giving antibiotics in the last minute, when she had one hour or 20 minutes to pass away, that night? That is another one. I think about it all the time.

Yes, she was (inaudible). She came here in January. She ran away from the clinic. She had a drip on her chest because they were starting (inaudible) and back to Woodroffe in Palmerston. Then he came back with her. ‘What is going on?’ ‘Because you ran away’, I said. She was scared. I could not have her next door because I was worried about her health and drinking. (inaudible) about my sister. I am worried about the drip in her chest. (inaudible). The next day I was talking (inaudible). I was talking to other people in the room (inaudible). It was shocking to lose her. She was talking strong yesterday. She never gave me that feedback saying, ‘I told the doctor that it is okay that I can have a meal or whatever’. There should be something there.

It is good that you guys are bringing and maybe that is the reason why you ask the community about this sort of thing. That is all my story for my sister, that they did not give me a proper answer, to let her pass away the next day.

Mr CHAIR: These conversations about clear communication in a hospital setting, a patient setting, a palliative setting and an emergency setting, we do not have these conversations every day. A lot of people are interested in what this report that we write about this will say. We want to make sure that we include these kinds of thoughts because this is now the second or third story you have told us today about unclear communication in a hospital setting before somebody passes on. Everybody needs that. It does not matter whether you are Indigenous or non-Indigenous or from migrant communities, lots of people have difficulty. None of us are medical doctors.

K McNAMARA: I would like to add that I think it is important that we are clear about what we have power over. I wish we were here to say, ‘What is everything wrong with the medical system?’, you know, bad communication. Unfortunately, we are here to listen to everything but also we have only been asked by the government about VAD. Do you know what I mean? Unfortunately, we are not here to fix every part of the medical system. We will listen to all your stories and we will pass them on, but we do not have the power to change all of that, particularly the government wants to figure out this question of VAD.

Ms JOSHUA: You came to the community because you have every right to find out what is going on. This is where the story happens. This is where the (inaudible) comes in about that last one. You need to know what is happening.

The INTERPRETER: [Kriol spoken.]

Ms JOSHUA: That is what I am saying.

The INTERPRETER: [Kriol spoken.] We are going through all that health system.

Ms JOSHUA: All the people are upset. They want to know what is going on. Everybody has questions about what is happening.

Mr CHAIR: Kat is absolutely right. We have been asked to look at specific things, but we also know some of these things we have been asked to look at have a strong interaction with other things.

One of the very strong interactions with VAD is palliative care. We know from the doctors, the Health department, that if you make a law for VAD, you also need to support more palliative care because what usually happens in other places in Australia is once this is available, people want more palliative care before they use this.

We want to know a bit about palliative care in Ngukurr. Can you tell us what services are available now or have been in the past, or where there may be a need for more services? How do you help people finish up on country now?

Mr KERLE: Is that the right words, ‘palliative care’, in the community, like at Rocky Ridge?

The INTERPRETER: [Kriol spoken.] I remember Brother William saying to me about that, saying that there will be no doctor or nurses here.

Unidentified speaker: [Kriol spoken.]

The INTERPRETER: [Kriol spoken.]

Ms GEORGE: We need transport.

The INTERPRETER: [Kriol spoken.]

Mr CHAIR: Tell me more about transport.

Ms GEORGE: (inaudible) CareFlight into our community.

ROBERTA: That happened before. CareFlight did that, yes.

[Multiple people speaking.]

Mr CHAIR: Sometimes it happens; you are right.

ROBERTA: But when the person has only a short time, maybe one or two days, they would then call family and say, 'Sorry, we cannot get to you because we are going to finish up any minute, any time'.

Mrs CARLSON: I have a question on the timeframe you have been talking about. When someone is sick, have they been sick for a very long time? What type of illnesses are we talking about?

The INTERPRETER: Mainly the diseases in communities are kidney failure, cancer and heart. They are the main three. We know already people are not healthy. We already know that. We try and encourage family to go to the clinic, but they say they have never been to that clinic. This is the truth that I am saying, and we cannot change them and stay this issue. But what we do culturally is to surround them and give them the love they need from us. That is part of that system too that we were talking about at the church.

ROBERTA: We comfort one another, each individual family member in one group.

The INTERPRETER: We try our best.

The other thing is they refuse to go to the clinic because they see that there is not enough support there as well. No doctor, and that is the problem.

ROBERTA: If somebody finishes in our community, the community all get together and we also go and share to the family, paying their respect. All of us do that. We do that all the time here, so nothing has changed.

Mrs CARLSON: With voluntary assisted dying (VAD) these are for people who have been diagnosed with cancer and some of those illnesses that they have been given a timeframe of, say, up to 12 months, so they are going to die and there is no more medication that can help them. They want to die earlier so that they do not suffer or they want to die with dignity.

Maybe what you are describing in your culture is that people are still trying to go and get medical help to live because we do not like people to die, we want them here forever, but there comes a point where their body probably cannot accept the medication that is trying to treat them. We have tried so long that it has pushed your timeframe now to be a very short timeframe and there is no turning back, and you are trying to get your community members back to country as quickly as possible to spend the longest time with your people.

We spoke about this in the church. If we use those words a bit differently with you guys, you still want help to die on country, but it is not a needle early in the piece like some people want. You just want help to come back and your people want to come back and die on country with family.

Ms GEORGE: That was a choice from the beginning and it is not a new thing; it has been way back. Our old people have been doing this for a long time.

Mrs CARLSON: Are you still okay with this other concept where people who have tried medication and their body still cannot take anymore medication and the doctor has given them a short timeframe, of up to 12 months, that their choice is to end their life earlier because they do not want to suffer? Are you okay with a law like that still for the Territory to have, a different option for other people?

ROBERTA: I do not know.

The INTERPRETER: [Kriol spoken.]

ROBERTA: [Kriol spoken.] You mob just asking too many things. It is confusing.

Mrs CARLSON: I probably understand. You would not use this. That is what I am saying.

ROBERTA: You know why. We cannot use that (inaudible).

The INTERPRETER: If somebody used it in Numbulwar, how would you feel?

Unidentified speaker: That is their choice.

[Multiple people speaking.]

ROBERTA: No, because it feels funny, out of place and does not feel good—wondering, confused (inaudible).

The INTERPRETER: [Kriol spoken.]

ROBERTA: [Kriol spoken.]

Mr CHAIR: The story about the drug you were telling us about before, who was that?

Mrs CARLSON: Her mum.

Mr CHAIR: That was your mother. I just wanted to check. That is what I thought. I was pretty sure, but I just wanted to double-check.

The INTERPRETER: She was a nurse. Her mum was a nurse and she knew which …

Mr CHAIR: Which drugs, yes. I have got that.

ROBERTA: Which medicine, and not only that, to tell you the truth, she was coughing. I said, ‘Stop coughing. Look at this. This is not an ordinary mucus. This is something.’ She knew already.

The INTERPRETER: [Kriol spoken.]

ROBERTA: When doctor (inaudible) that sick in the cough and looked at weight going down, he knew himself (inaudible). ‘How you know?’ ‘I am a nurse. I know.’ (inaudible) There are other things like medicine (inaudible).

Mr CHAIR: Did that medicine help to just reduce pain?

ROBERTA: Yes.

Mr CHAIR: Or did it help her to also pass?

ROBERTA: Also pass.

Mr CHAIR: In honesty, that is the same thing as this.

ROBERTA: It is the same thing as that. Yes, I know.

The INTERPRETER: It should not be at the clinic—right? Because that is illegal.

Mr CHAIR: What I am saying is that …

Unidentified speaker: (inaudible).

Mr CHAIR: No, it is not …

K McNAMARA: It is not the same medication, no.

[Multiple people speaking.]

ROBERTA: What do they give you up here? It is an option that you—sorry.

Mr CHAIR: No, that is fine.

I was going to say that none of us can guess which medication was what, so we should not guess that. What we know is that this much medication will cause pain relief. More of the same medication will cause someone to pass on. That happens all the time.

There is not a specific—in every other state and territory around the country, it is not that they use one medication; they use several different medications.

Did you want to clarify that?

K McNAMARA: I wanted to make it clear that none of us are medical professionals. If we are wading into the idea of different medications doing stuff—I know you are being generic about it, but just so everyone understands, none of us are doctors or nurses.

Mr CHAIR: Yes, that is important to clarify. We are saying that it does not matter which medication we are talking about, it is the idea …

ROBERTA: There are all different drugs.

Mr CHAIR: Yes. It is the idea that we want to know …

ROBERTA: (inaudible).

Mr CHAIR: Yes. It is the idea that we are interested in; how do you feel about the idea? Again, in the every day—let us say now in the future in the clinic here if there is somebody who is very sick, would you want for those people to have pain relief to help them, not necessarily to help them pass on, but just to help them when they are suffering? That is largely what we call palliative care at the moment. In the hospital we can do that, but we do not do that as much out in the clinics. I am trying to work out whether that would be something we want more of here. Some injections, of course, can help someone pass on, but some injections are just pain relief—like you said, the one in the back.

K McNAMARA: I am worried that we might be confusing the two. We still have to keep the idea that the injection for voluntary assisted dying is very different from the medication that you get in the clinic. I am worried that somehow …

Mr CHAIR: Sure, yes.

The INTERPRETER: That is what I said. [Kriol spoken.]

ROBERTA: How can this lady know what is in and out? That is the question to all of you.

Mr CHAIR: She is actually more medically attuned …

[Multiple people speaking.]

K McNAMARA: No, I know what she is saying …

Mr CHAIR: Everything you are saying is bang on, but the honest truth is …

ROBERTA: This is the honest truth I am telling you.

Mr CHAIR: Absolutely. The same drugs that were used in 1995 are the same drugs that they are more or less using now—morphine, sodium pentothal. It is all the same class of drugs; nothing fundamentally new is happening. She is 100% right. What she is describing makes perfect sense.

ROBERTA: It is similar to that. There is drugs similar, but doctor, when they find the answer, they are not telling you, they keep it secret. There is history …

[Multiple people speaking.]

ROBERTA: They do not tell the blackfella, does not give it to the right person—they keep it to themselves and then really confidential, yes. That is (inaudible).

Mr KERLE: If I can , I will try to sum up. The way things are now in the Territory, with your mum, she had to do it in secret. It is only because she knew the right drugs and she knew what she wanted …

ROBERTA: No, she did not do it in secret. There were two doctors and a nurse. So, when they came to ask to give her those medicines, she said, ‘No, I know which one I really want’, and she asked—she knew this drug.

Mr CHAIR: Your mum was lucky that she knew. Also, she was lucky that those doctors and nurses were willing to help her. Some doctors and nurses are too scared to help in the situation …

ROBERTA: [Kriol spoken.]

The INTERPRETER: [Kriol spoken]. That is what we were trying to discuss today; this is an open discussion about this medicine.

ROBERTA: [Kriol spoken.] and just say I do not want it.

Mr KERLE: Because the problem is right now if a doctor helps someone like your mum, they can get arrested by the police and they can go to jail for that right now.

The INTERPRETER: [Kriol spoken.]

ROBERTA: [Kriol spoken] drugs that numb your body and stop you from paining.

Mr KERLE: Yes, if this one happens then they can do it openly and legal …

The INTERPRETER: And ask your family.

Mr KERLE: If someone wants to, there is a process.

The INTERPRETER: [Kriol spoken.]

Mrs CARLSON: There is time still.

The INTERPRETER: [Kriol spoken.]

ROBERTA: [Kriol spoken.] I know what you are saying, but in our culture, you know, we cannot break our promise too. If that sick person asks to go back and finish off with their family, you can never break his promise; that is his will. You can never force that person to get that needle.

The INTERPRETER: [Kriol spoken.]

ROBERTA: But you always have to listen to that sick person first.

The INTERPRETER: [Kriol spoken.]

ROBERTA: You listen, one voice and everybody together.

K McNAMARA: I guess that is where some of the difficulty is when you have explained your three—group chats—you get permission. In Western culture it is just one person; you just decide. You know with the consent form, the idea is you just say yes or no. Here is the tricky part; you guys are like, ‘How do we have a …

The INTERPRETER: The thing is with that they will not agree with this one—the one way.

K McNAMARA: That is good, and we are taking all this information down.

ROBERTA: (inaudible) will not agree with that, that is it. I am sorry, guys, but that is it.

The INTERPRETER: [Kriol spoken.]

ROBERTA: But then you take again.

The INTERPRETER: [Kriol spoken.]

ROBERTA: They are not going to agree because not one sick person would agree for that. You will get the same answer.

Mr KERLE: You said before about people coming back from hospital to finish up on community.

Ms GEORGE: Yes, my mum. I would have brought my mum.

The INTERPRETER: A lot of our great-grandparents—80, 100-year-olds, that age group—were brought back home.

Ms GEORGE: She was in aged care and then she went to them, but they asked her. The doctor told me, 'Your mum wants to go back'. She passed away here, my mum. She came back and passed on here from palliative care.

Mr KERLE: So they are in somewhere like Rocky Ridge and the doctors are having to do a lot of work to keep them alive, and then they come back to community and then take away the care …

Ms GEORGE: She was only here for a couple of days, mum, a few days and then she passed on.

Mr KERLE: When that happens is there that the three discussion with community?

Ms GEORGE: Yes, family, family members and relatives for the other family member that came and saw my mum when she passed on.

Mr KERLE: Is that before she comes back from hospital or when she is here?

Ms GEORGE: No, when she passed away here. That was like five, six or seven years ago. But she wanted to come back here, my mum.

The INTERPRETER: Recently I lost my grandmother and she had cancer. This is the time when my dad passed and she wanted to stay for my dad's funeral, and we knew she was going to leave us. We were asking her and asking the doctors, 'Why do her need to go to Darwin?' They said, 'We need to treat her'. What is the point when she is going to pass away in one or two weeks?

That is the other thing, they keep pressuring our elders to go and get medication in Darwin. We do not want that. When they make their decision, we want them to accept it and stay here, and not have the clinic keep coming, 'We have got to take this old woman back to Darwin'. She went. She passed. We wanted her here.

ROBERTA: That is the choice between sick people. If they want to stay back home, let them be.

The INTERPRETER: I cannot believe that happened, because they kept pushing her. She was already dead, like walking, like dead man walking.

ROBERTA: We have one more sick lady, a relative of ours. She is in hospital.

The INTERPRETER: Yes, and she wants to come home.

ROBERTA: She is coming home.

The INTERPRETER: We have one already who wants to come home.

Mr KERLE: That is palliative care.

ROBERTA: Yes, and she refused dialysis. That is her choice.

The INTERPRETER: Because they know they suffer when they are on dialysis. That is the other thing. That is what people think and see. Using dialysis is a way of suffering. When they come home without dialysis—my dad died without dialysis. He already knew he had everything going, so he just passed away.

ROBERTA: I have kidney problems. I am on stage 4. I am wondering how I will get really sick. I am still walking and still here. The last time they took me to Darwin, 'We will put you on dialysis'. 'Sorry; I do not believe in that thing. Sorry; I am going home. That is my choice', I said that to her.

Mr CHAIR: Tell me about telehealth. Do you use telehealth here much?

Mr KERLE: Does everyone understand what that is?

The INTERPRETER: We had it recently. [Kriol spoken.]

ROBERTA: Once you get appointment, you can just go for appointment. They send the request to the clinic and then tell you what day your teleconference is at the clinic. Someone picks you up to go to the clinic and you speak to a camera like this.

The INTERPRETER: [Kriol spoken.]

ROBERTA: I am supposed to be on dialysis. I am on stage 4.

[Multiple people speaking.]

K McNAMARA: And you feel okay?

ROBERTA: I feel fine (inaudible).

Ms JOSHUA: Here in the clinic, we just had the doctor here before. He used a phone …

[Multiple people speaking.]

Ms JOSHUA: You go through the nurse, and then you speak to the doctor about your medication. Sometimes they do not have the medication for you in the clinic, so you run out. You have to tell them and let them know, explain to them. Then we have to call the doctor, wait for (inaudible). You will wait for two weeks, sometimes, for that to come in. We do not have a doctor in the clinic here.

Mr CHAIR: That is why I am asking about the telehealth, in particular. A lot of places do not have doctors in community or nearby. We are trying to understand in every place how much people are using telehealth.

The INTERPRETER: The only time people use telehealth is when somebody is about to pass away.

Mr CHAIR: That is interesting too. The only times you are using telehealth at the moment are when somebody has almost passed away. When that happens, what does that look like? Can you describe to me what that telehealth session looks like for you?

The INTERPRETER: I have a feeling about one. I have heard of one recently. That is when they make the decision or sit and listen to when that person passes away up in Darwin. (inaudible) come home. If they want that person to come home, they arrange something to bring them home if they want to finish here. The leaders at the church had a good answer to that one.

Mr CHAIR: It is a good answer for us as well because, I guess, what the healthcare system would like to believe and say is that if we use more telehealth, we can help more people. They already use telehealth, is what we understand, but how much they use it, we are not quite sure.

Ms JOSHUA: Not much.

Mr CHAIR: Not much.

Ms JOSHUA: That is what I was explaining about my sister. She was in Darwin and I was talking to the nurse in the clinic (inaudible) so I was speaking to them and describing to the nurse and doctor, explaining about, the health of my sister. They do that only when the family is not there and they are not going to live longer, so they only have a short time to stay. There is an option for the families to get picked up by the health truck and take them there to the clinic.

The INTERPRETER: You might have been able to telehealth before aunty finished doing this (inaudible).

Ms JOSHUA: (inaudible) went up there with her mum; she was there with her mum. I mentioned earlier that the next day she just was gone. I do not know what really happened there, but it is good to have the telehealth in the clinic there. It is really important because sometimes you have the bus come in, the family chat on the bus. Somebody messages or calls them. In Darwin, Katherine or Mataranka now (inaudible).

Mr CHAIR: Is it okay to have conversations about finishing up, using telehealth? What do you think?

Ms JOSHUA: You have to have your certain people beside you. That is what Melissa has mentioned. You have got to have your daughter or your son and family there beside you.

The INTERPRETER: I will give an example. [Kriol spoken.] There was not just five people; there were the people plus the whole Ngandi tribe was at the clinic [Kriol spoken] because they want everybody to know that his time was coming and not just two people. That is what happened that day. People felt good because they were there representing tribe, culture and they made their decision. Telehealth I think is good, but family is better to bring the loved ones home.

Mr CHAIR: Does this situation—we have mostly been talking about older people and people with cancer and people with kidney problems, but we also talked about younger people like your granddaughter. Can we have these same conversations when it comes to younger people using telehealth? Is it the same, young or old?

Ms JOSHUA: It depends. It is a different way of losing someone. Maybe it will be better. We have another three more funerals coming. For example, if one of you or somebody can look at how we do our funeral, because the box will come into the hospital and we stand in a row to meet the driver that carries the box. You do not know how to stand with the people there. If you are a cousin, you are going to have your poison cousin to be responsible for the box. That is how it goes to our culture. That is an example, when there is a funeral if wish you guys would have been here, you would have seen how it goes. The cultural people will come in and have their song because every person has the song from their country where he comes from.

Mr CHAIR: Out of curiosity, when are those funerals that you are saying that are coming up?

Ms JOSHUA: Maybe sometime next month.

Mr CHAIR: Next month?

The INTERPRETER: There is no date yet …

Mr CHAIR: No dates are set yet?

[Multiple people speaking.]

Ms JOSHUA: We are still waiting, but like I said, when it comes to funerals, you see what is happening there. You will see how certain people are in charge of the body. Your son and daughter are not going to be in charge when you pass away; it is going to be your cousin and certain people that, yes, are making sure that everything is going well. Then they free you, ‘Okay, you can have the funeral now, tomorrow’, and then everything goes well.

Mr CHAIR: Does that process run smoothly usually, from when somebody finishes up? Let us say they finish up in Darwin and then the body arrives here, is that process usually smooth?

Ms JOSHUA: You would have two or three people go up to Darwin to come with the box. Sometimes they do that. It is not all. Sometimes, yes, they go by plane or go by road. They choose it in certain ways.

The INTERPRETER: The process is not usually smooth. Sometimes people, like in other cultures you have that funeral straightaway.

Mr CHAIR: Sometimes, yes.

Ms JOSHUA: Some people have it straightaway.

The INTERPRETER: But in our culture, you have to wait one month, two months or three months because, as we mentioned, the three people have jobs. They are going to contact this person in this community to attend. This person in Melbourne if they have a relative there that needs to attend. That is why the timeframe is like that. Then when they meet, they start working, you know, (inaudible) and all that kind.

Mr CHAIR: This is after they have passed, you are talking about?

The INTERPRETER: This is after—before funeral, there is work needs to be done. That is the cultural way. We cannot talk about that. We sit with elders and you understand it that way. That is inside where we do cultural stuff, but outside is the open discussion where we tell you the process. We wait three months, two months, because these three people will do their job. After that, we bring family home.

Mr CHAIR: This report also is concerned with what happens once somebody has passed away. Who notifies the Coroner or where does the body go or how long things take. That is why I am interested in this as well.

The INTERPRETER: We all know Yugul Mangi Corporation, they get the information, like applications you have to apply for grants, like through NLC, to pay for the coffin and pay the transport. Then they tell family members. It is usually—I just did that yesterday for a family. Then they have to sign things for the Coroner report and all that stuff. That needs to be done first. Then they do …

Ms GEORGE: Then they give (inaudible).

Ms JOSHUA: When the body comes down from Darwin, it stays overnight in Katherine or sometimes maybe two weeks because you got another box that is going to Beswick or Barunga. That is another one; it is the way of (inaudible). You got one from Numbulwar. Numbulwar is a bit closer to us here and you got (inaudible). We cannot have the funeral on the same day, we have to wait for whatever comes first for that family, we have to wait. Everybody has to wait in line. That is how we have to sort it out for the funeral.

Unidentified speaker: (inaudible).

Mr CHAIR: That was a not-very-subtle way of them saying we have to wrap up soon anyway.

First of all, thank you for everything you guys have been sharing. I have to ask this. All of the stories you told us today are really useful for us. We would very much like to include them in our report and our submission, but we need your permission to do that. Would it be okay for us to use your names and these stories that you have told us today as part of our evidence?

Mr KERLE: Or do you want to let us use the story, but then keep the name private?

Ms JOSHUA: Yes, we can be silent and you can have the story. That is okay.

Mr CHAIR: Okay. We will anonymise. We will not mention who you are individually, but anything we report from here would be a person, a respondent, but it will not identify who you are from this community. Is that okay?

Ms JOSHUA: I am happy with that, yes. This is one of the feedback. We need that feedback.

Mr CHAIR: That is right, yes. It is very useful for us to be able to, obviously, use the information.

We have another session starting with all the community health workers in five minutes. How about we all take five minutes off and stretch our legs?

The committee suspended.

Roper Gulf Regional Council

Mr CHAIR: Let us make a start. Thank you very much for being patient. Sorry; we are running a little bit behind. We will get everyone in the room to introduce themselves quickly, so everybody knows who is who.

Very quickly, my name is Tanzil. I am one of the members of parliament. I am the Member for Fong Lim which is one of the Darwin city seats. I am the Chair of the Legal and Constitutional Affairs Committee. As you know, we have been asked to look into voluntary assisted dying and specifically the 2024 report.

Mr YOUNG: Hello, my name is Dheran Young. I am the Member for Daly which takes in Wagait Beach, Dundee, Berry Springs and all the way down to Wadeye and the Thamarrurr region.

K McNAMARA: I am Kat. I am the Member for Nightcliff. I am on the committee. I look after Nightcliff, Coconut Grove and Rapid Creek.

Mrs CARLSON: Hi, I am the Member for Wanguri which takes in Wanguri, Leanyer and Muirhead.

Mr KERLE: G'day, I am Matthew Kerle. I am the Member for Blain, so I take in Moulden, Woodroffe and Bellamack.

K McNAMARA: We also have our lovely parliamentary staff here with us.

Mr KERLE: Caroline, Katie and Georgia.

Mr CHAIR: For everyone's benefit, if you guys on the Teams call and in the room want to introduce yourselves as well.

Ms GREER: My name is Cristie. I am based in southeast Queensland at the moment, but I work for Roper Gulf. I was up there for the last three years. I had never been to the NT or worked for a remote Indigenous community before, so I came across a completely different experience to the urban setting that I have grown up in. It was a complete eye-opener. I worked my way up in Roper Gulf. I am now the programs manager for essentially the community services side of things—everything from creche, so day cares, through to our aged-care services …

[Loud noise.]

Mr YOUNG: There is some sound coming through. We should be able to hear you clearly now, Cristie.

Ms GREER: Sorry; did you miss some of that?

Mr YOUNG: We got up to where you work for community services and aged care.

Ms GREER: Having no experience up until four years ago, I did not know what it was like to work in the NT or with some of our remote Indigenous regions, but I do have a strong background in community services. I worked my way up from a coordinator position to the programs manager. I essentially deal with the funding side of everything we do within community services.

Under me is Nicole. Nicole, before she introduces herself, has just come onboard with us and has a strong background as a clinical nurse and has worked in our remote Indigenous communities as a nurse.

NICOLE: I am Nicole. I am the incoming clinical aged care and disability manager for Roper Gulf. My background is in intensive care and emergency nursing. I spent 15 years as an ICU nurse in Melbourne working in all of the big tertiary hospitals. I left clinical nursing in 2015 and started working in aged care and disability for about 10 years, maybe a little bit less. During COVID I went against the grain. A lot of nurses left bedside nursing during COVID because it was fairly taxing, but that actually drew me back to clinical nursing. I had been working as a rural and remote nurse throughout the Top End, the Kimberley and the NT until I took this role with Roper Gulf.

Mr CHAIR: Thank you, Nicole. In the room we have?

LINDA: Hi, my name is Linda. I am working as an aged-care coordinator for Ngukurr and Urapunga. Now for three months I work here, and I am staying 60 years now. I stay in Ngukurr.

Mr CHAIR: Fantastic.

All right, guys, we have got about 45 minutes. We have had a really productive day today talking to people from St Matthew's church, local residents, community groups—everyone, basically. It has been very helpful. We are keen to ask you some more pointed and technical questions than some of the rest of the group.

As you will know, our job as a parliamentary committee is to look into this report, the 2024 Report into Voluntary Assisted Dying in the Northern Territory, which has 22 recommendations and a proposed model, if you like, for how VAD might work in the Northern Territory if we were to go forward. The authors of this report, as well as other people, acknowledge that perhaps more consultation could have been done in remote areas to find out what people out bush think about VAD. That is essentially what we are out here doing.

We are here today. This is the first of about a dozen days over this month that we are spending in various communities. What we really need to understand is on the ground how people feel about it, but also from the people who service the people on the ground, what the lay of the land is at the moment in terms of palliative care, access to services, telehealth—I could go on and on.

It would be helpful if you guys might start by giving us a bit of a description of where Ngukurr is at in terms of healthcare services, what its residents' healthcare needs look like and whether there might ever be any use in there being something like VAD available in this community.

Ms GREER: Linda, I know that you are a little bit shy to talk up about this. You know most of our clients and you work with a lot of the old folk in (inaudible). Essentially, your opinions are worth bringing up.

How do you feel about the current level of services that are being provided?

LINDA: For the palliative care or just (inaudible)?

Mr CHAIR: Either/or for us.

NICOLE: Yes, maybe start generally, Linda, and then if you guys want to dive into anything that you bring up, we can do that.

K McNAMARA: If it is easier, you can come closer.

LINDA: Generally, we provide in-service meals and laundry service and some personal care—shower—social group and individual. That is what we normally provide there. Personal care, like for showering—people are shy. In here, male and female, they cannot accept it, so we cannot provide—we have female; we cannot provide male clients to have their shower. Also, females are shy, so only they are allowed to really close family, like that.

Mr YOUNG: Is that service for the aged care …

LINDA: Aged care, yes.

Mrs CARLSON: Like home care.

Mr YOUNG: Home care patients, yes.

LINDA: They are just being—we actually have been to see the OT or (inaudible) specialists like that, but we have the good platform in aged care, so HCP package. We can do the referral and then they can see the table, so they can go telehealth. That is really good, but still some other specialties we cannot really.

Mr CHAIR: What about, Linda, palliative care?

LINDA: Actually I do not have that experience; only one client was palliative. He was not our client, but he came here and then he wanted to get the service in (inaudible) but after a couple of months he went back to Katherine and that was all.

K McNAMARA: How do people get referred? Are you the only aged-care service here in Ngukurr?

LINDA: Yes—provider.

K McNAMARA: Okay, the only one. I guess it is a small enough community that you know everyone. How do they get referred?

LINDA: I can hear from anyone that somebody needs a meal service and somebody needs help, I will talk with them or they come to me. Also I will ask staff always around the community to (inaudible) and then they will talk. I can hear, I can go, they can come.

Mr YOUNG: At the aged-care facility—is this an aged-care facility with beds?

LINDA: It is not for sleeping; it is providing service and they come. It is not someone coming and sleeping, we do not have that.

Mr CHAIR: It is not a facility (inaudible).

Mrs CARLSON: Are there any respite facilities?

LINDA: No.

Mrs CARLSON: None at all.

LINDA: But we can send …

Ms GREER: Only day respite, which is provided to the clients, but there is no carer respite.

NICOLE: If I could just include, I know you were asking about the referral process for anyone who required palliative care, we do not have any active palliative care clients out here in this area at the moment, but what we do in each of our communities is track our vulnerable clients. Each month we will have a meeting to discuss the vulnerable clients in each area, and that is probably the most likely area of where someone requiring palliative care services would come from.

Ms GREER: In doing that we have had some palliative care clients come back on country. It was known that was the purpose, for them to come back on country. That was in Numbulwar maybe 18 months or two years ago where the client was under the care of the clinic out there, who was under NT Health. In Ngukurr and the rest of our region, it is all Sunrise Aboriginal health organisation, but Numbulwar falls under the Department of Health. We were able to have a palliative care client come back to country and he was—because up until now, including right now, we have not have had a clinical nurse on staff. As an aged-care service we have not been able to provide our clients with the opportunity to come back to country when they were in a palliative state.

Mr CHAIR: Cristie, a lot of the people we have spoken to today have expressed a very clear view that they would like better services to be able to come back to country, particularly when close to finishing up. One of the things that we have learned today as a group is that voluntary assisted dying has very specific meanings for us, but to assist somebody to die well and compassionately perhaps we could be thinking about these terms more broadly.

The other thing we know is that across other states and territories where there are VAD laws, once VAD laws have been introduced the need for palliative care has risen. We know that we cannot extricate one thing from the other. It would be useful to get a stance from you guys about if there is a capacity deficit in palliative care here at the moment. For example, if the NT was to move in the direction of VAD legislation, what extra we might need to do to be able to cover both things separately.

NICOLE: You just cut out there. What was the last one?

Mr CHAIR: My apologies. I was saying that if the Northern Territory did head in the direction of VAD legislation, then what else might be required in the palliative care space to support that so that one did not come across to the other?

NICOLE: I can give you a one-word answer for that if you like.

Mr CHAIR: Please do.

NICOLE: GPs. There are no GPs in Katherine at the moment. Any voluntary assisted dying requires a prescription from a GP. If the NT follows the rest of the states that have VAD laws in place already—coming from Victoria I have a little bit of a leg-up because our legislation has passed—it requires a doctor to administer the medication; it cannot be self-administered.

They are looking at logistical issues, first, and, second, which doctor is going to prescribe it? Which doctor is going to administer the medication and who pays for that doctor? That is just off the top of my head.

Mr CHAIR: No, they are excellent points. They are the kind of things we would like to discuss some more.

The 2024 model proposes a standalone centralised service that would be run, probably out of Darwin as a major urban centre, to then operate, if you like, FIFO or on standby or with some degree of interaction with other state and territory bodies, to be able to provide a first assessment, a second specialist assessment and then apply or administer a VAD solution at some point.

To do a lot of those things, we have heard different testimony about the importance of telehealth. At the moment, there is a federal prohibition, as you all know, in relation to inciting people to end their own life, so there are restrictions on what can be done via telehealth.

Can VAD be workable anywhere outside the major centres without changes to telehealth? Would we envisage a future where if VAD was available it would be about on-ground consultations and then having to take people back to a centralised site?

We are trying to envisage models, if you like, that will work for the Territory.

NICOLE: Essentially, given the NT and the way the seasons work up here, you are going to be battling Wet Season versus Dry Season. You are going to be battling road closures versus roads open. Do they need to fly in? Can they drive in? Yes, I think the sensible way would be to look at seeing if we can have the telehealth rules changed because that would open it up to a lot more people. Then you would be able to remove the barriers that road closures and Wet Season and maybe the weather is too bad—we have somebody who wants voluntary assisted dying from a remote community where the only way in, in the Wet Season, is to fly, but the weather is too bad for them to land. That happens quite often, where things are bad, we have often had patients where we were unable to evacuate them by RFDS or CareFlight due to weather. That will be a consideration if you are looking at the FIFO model.

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Mr CHAIR: That is fine. We did not read the privilege point for the record. Should we read that?

Ms WILLIAMS: In terms of the opening statement, you worked your whole way through that or not?

Mr CHAIR: We did not do it today, no; we just launched straight into—we went to roundtables. We can certainly do it again now if you want.

For the record, guys, we have a script that we would have gone through at the beginning which was to acknowledge country and traditional owners and pay respects to elders and also to thank everyone for being here. Then moving on, if you like, from introductions and what we are discussing to mention that, obviously, we are talking about sensitive matters today and if anybody needs a break or needs a break from what they are talking about to be able to let us know so that we can take a break, noting that support services are also available. We have had different protocols for what we are doing in terms of recording. As we discussed at the very beginning, we were recording this meeting via you guys today, and we would like to publish the record because this is a formal proceeding and, as a result, protection of parliamentary privilege will apply as well.

We have done a round of introductions which I think we can take to be stating your name and the capacity in which you are appearing, because we know who everyone is.

[Loud noise.]

Mr CHAIR: The ghost in the machine keeps turning up, just to make it exciting!

Really the only question then is to the manner of what is being said here today

[Loud noise.]

Ms WILLIAMS: There is a bit of noise in the background, I think from Nicole.

[Multiple people speaking.]

Mr CHAIR: Can you hear now? All I was saying is that the only question becomes for what we have discussed to this point, after the fact these guys will be able to review the transcript if necessary.

Ms WILLIAMS: It might be that we redact that discussion we have just had in total.

Mr CHAIR: There is no …

Ms WILLIAMS: In terms of just this latest topic that we just spoke about in terms of practices in the field regarding end-of-life administration of …

Mr CHAIR: The point is these guys could review that testimony and decide whether they want that redacted or not; is that not right?

Ms WILLIAMS: And we will do that as a committee as well when we get the transcript—yes?

Mr CHAIR: Sure, before it goes out. Anyway, the transcripts emanating from this we will review as a group and then go from there.

Getting back to where we were in terms of services that are provided out here, GPs, Nicole, was the first point you were making in relation to the workability of any of this.

Are you guys familiar with the model that is being proposed and the details inside it? You do not have to be. It is okay; it is not everyday reading.

NICOLE: Can you just repeat that last section?

Mr CHAIR: Sure. The 2024 report has 22 recommendations in it and essentially proposes a model for how VAD might work in the NT. Do you guys have any knowledge of that model or any thoughts about it?

NICOLE: Is that the document that was included with the meeting request?

[Multiple people speaking.]

Mr CHAIR: To clarify, the document that you guys would have received was the consultation paper that we produced, which is essentially our take on this report. We are the authors of this one that you would have received. In relation to what we have provided in the consultation paper, do you have any specific thoughts about any of those recommendations about the model that has been proposed?

NICOLE: I have not actually seen the recommendations.

Mr CHAIR: Okay. The recommendations …

NICOLE: Is that …

Unidentified speaker: (Inaudible).

Mr CHAIR: The 22 recommendations are in this paper that we presented, but they are reorganised, if you like, under topics. It was rewritten so that we are asking about 'eligibility', 'review and oversight' et cetera. In terms of those criteria, or in fact anything in the consultation paper, did you have any feedback for us in relation to what is in the consultation paper at the moment?

NICOLE: No, not off the top of my head, but I probably would like a chance to go back and review it again …

Mr CHAIR: That is fine.

Ms GREER: Yes, agreed.

Mr CHAIR: That is fine. We obviously have a process for written submissions being available until the 15th. If you want to go back after the fact and have a look at anything and send us anything in writing as an afterthought, that would be very handy as well.

NICOLE: Yes, I will do that.

Ms GREER: Nicky and I can certainly get together because we did have a chat about this. Essentially, I want to clarify how do you care for Indigenous clients where they want to move back to country, knowing that they will die on country and may not receive the resources to keep them alive? Is that included under voluntary assisted dying?

Mr CHAIR: Not at the moment, Cristie, no. At the moment, none of that is incorporated in this report that was done in 2024. It has not been countenanced in any other state or territory either. Part of what, I guess, we are getting a sense for today is whether or not we should be thinking more broadly about what each of those words, 'voluntary' and 'assisted', mean. It would appear from what we heard earlier that some people would like choice and help to finish up. That was the phrase that we got lots of traction with when we were talking to community groups. More broadly—because today is just the first of our month-long consultations out bush, basically—we will be asking questions about how might we offer more choice and help to finish up.

Ms GREER: That is one of the hard parts. I know that the aged-care standards are changing, but it would put clients, for example, in Darwin that are from Ngukurr. You have got two conflicting standards, where you have choice of dignity and then you have restrictive care. You have choice of dignity, where a person is allowed to be in a space that they want to, if they are sound of mind and are able to choose where they want to be. Then you have the opposite side of that which is restrictive care, which is saying, 'No, it is better for your health to do this', but it goes against the choice of dignity.

If someone is of sound mind and they say, 'No, I want to reject the care and go home', there might be an aged-care centre in Darwin that calls us and says, 'This person wants to come home', and we say, 'We are not capable of providing care to the level that they need', it becomes a really difficult space for us.

There needs to be some clear boundaries about how that will work for someone to come home, where their family wants them and that is where they want to be; there is not the red tape, essentially, which is that difficult space. Nicky, you might be able to comment some more on that.

NICOLE: Yes, I think you are right. I think what you are referencing is in (inaudible) where a client or a patient has the right to reject something, even though it is going to be detrimental to their health. You are right; if there is no (inaudible) impairment and they are of sound mind and they are able to make the decision, they are absolutely able to do that.

I think where the VAD laws will come in handy with this sort of situation is when you have a patient in Ngukurr, for instance, who is in Darwin hospital. We know that they have not got long to live; they want to come home to die on country. People like our organisation, that is quite—that is an emotional thing because we do not have any of the things set up to make them comfortable and help them do that, but they are insistent on coming home. In all my years of working as a remote nurse and as an Indigenous woman myself, I have never met an Indigenous patient who has said, ‘Oh, well, if that is the case then I will just stay in hospital and die here’. They all want to go home on country. It is just a matter of how comfortable and how peaceful their death is going to be. It is as simple as that.

If the VAD law is going to help in those tricky situations where the patient is really saying, ‘I want to go home and I want to die on my home country’, then it will be good to have some resources to put in place to be able to support them and not to feel that panic that most aged-care providers are feeling, ‘How are we going to support this person to have a good death?’

Mr CHAIR: Right now, Nicole, as you point out, none of that is countenanced at all in any of this documentation. It is a really useful opportunity for us to try and put that perspective into the report we put back to parliament regarding those definitional issues.

I will hand over to some of my colleagues because some of them will have questions as well. Kat, do you want to have a crack?

K McNAMARA: I will let you guys go. I am still writing my notes.

This is really great information, thank you.

NICOLE: You are welcome.

Mr KERLE: I will kick off with my observation, and then you guys jump in when you feel ready.

In our terms of reference it was to look at the things from the report last year, where it could be improved, things where they had not perhaps consulted as fully as they would have liked. I think today has really proven the worth of this inquiry because, as the Chair said, going through that report, all these issues of dying on country were not—there is a little bit there in appendix 9. Today it has really been driven home how important it is.

We have heard a lot of evidence, even though it is not really VAD, but there is a lot of palliative care where people are choosing to withdraw from treatment to come home to country, so they can be with their loved ones and go through ceremony and do all the culturally appropriate things, and that is just so important. I think that is going to be a big part of the report we do.

NICOLE: Can I just say that, at this stage, because of the lack of VAD laws in the NT a lot of these clients or patients are having to make a decision between Darwin and country. I am just trying to put this in the most PC way possible, in order for them to die on country, which is the most important thing to them and their culture, they have to forgo a comfortable death, the way things are. It is that simple. They will choose that every time. I have seen it time and again. They will come home with not the right palliative care, with not enough staff to look after them.

Just while I think about it, I would highly suggest that you guys meet with reps from Sunrise clinics throughout our region because it is not going to be Linda who will be providing clinical palliative care to these people; it is not going to be the aged-care workers; it will most likely fall on the shoulders of the nurses out at these Sunrise clinics.

K McNAMARA: Just help us paint a picture. As someone not from a healthcare sector, in a perfect world it is great, people do not want access to the actual medication for voluntary assisted dying, but what they want is to be assisted to come home and die on country. What does that actually look like in a place like Ngukurr in terms of are they at home; do they need a facility; is it like day-to-day support; what level of nurses or palliative care needs to be there?

Ms GREER: Linda, can you just maybe paint a picture of one of your clients, like an HCP client, that you can just describe how many people were in the room and how many occupants in the house, from a firsthand basis.

LINDA: There is normally like 20 people, or more than 20 people who live in one house. All the family is looking after the client, but it is really hard to bring him to the clinic. There is no GP and only allied health, and you need to wait a long time. He cannot move properly, so it is hard for the family to bring him. Sometimes they go there and the clinic is closed and they have to come back. It is difficult for them.

Mr KERLE: Sorry; just to clarify, you said 20 people. Is that for the end-of-life cultural obligations or is that just 20 people …

LINDA: Living.

Mr KERLE: Twenty people living in the house.

Ms GREER: So, we essentially have three-bedroom houses with five, 10 or 15 people living in them, up to 20, so we may have an aged-care client that when we supply a hospital bed, whether or not they use it depends on us being able to (inaudible). We take on aged-care clients who do not have beds. If you have a three-bedroom house and 20 people living in it, you know that 18 of them do not have beds.

NICOLE: I think from a clinical perspective some of the things that you are looking at—I will give you a hypothetical of a (inaudible) patient who is from an Aboriginal community who is 65 years old. We know that the Indigenous population has a high incidence of kidney disease, RHD, ischaemic heart disease—all of these sort of things that require more and more care as they get towards the end of their lives.

A very common occurrence would be someone with chronic kidney failure who has gone to Darwin hospital because they are end-stage now; nothing else is working, medications are not working. They want to come back to community, but they need three times a week peritoneal dialysis where they will (inaudible) in their stomach, the PD fluid goes in, it stays there for a certain amount of time and then gets emptied out. A lot of those patients are taught to do that at home, but at some point even that is not enough, so they are going to require Lasix, which is a medication, to offload extra fluid so that it does not overwhelm their kidneys and their circulatory system. They are going to require pain relief and sometimes up to three times a day and checks in. That puts an extraordinary amount of pressure on already overworked nurses out in these clinics. I am sure the nurses from Sunrise will back me up on that. It also means that people like Linda, they have this person who is on their vulnerable client list now and it requires an extraordinary amount of time and coordination.

The things that you are looking at for voluntary assisted dying patients who are coming back on to country are extra nursing hands to be able to administer medication, because at some point the client becomes too ill to actually make it into the local clinic. They cannot get in and out of their bed, so they will often we use both drivers who go and collect them from their home, bring them to their clinic appointment and then take them home. A lot of times at the end-of-life stage, they are just too tired, especially if it is a respiratory or COPD which a lot of Indigenous people have because of the high incidence of smoking. It happens with any cardiac and kidney problems. Their exercise tolerance reduces to five metres, so they literally cannot even make it out of their bedroom to the front door, let alone into a car and into the clinic. There is extra pressure there.

You have to find nurses—mobile—to go out to their houses. It puts more pressure on the ambulance that is out in the community, because a lot of times they only have one—and if the ambulance is out on another call. There is going to be lots of extra resources that will be needed to be able to bring it forward into these communities where you have got someone who is actively using the voluntary assisted dying protocols.

Mr CHAIR: Nicole, in the report there is quite a lot of reference to the role of nurse practitioners, potentially or hypothetically. We know that there are shortages of nursing staff across the Territory in lots of different places. Could this kind of solution be workable in the Northern Territory utilising existing staff, or would it simply be unfeasible unless you had extra people on the ground?

NICOLE: I think that would depend on the community. I have worked in two nursing posts and in larger areas like Maningrida where the clinic is extraordinarily well funded with five or six different programs running and up to 15 nurses on staff. That is the best-case scenario.

I think you are looking at two different staffing options. Nurse practitioners will be great, but there is a lot of problems around that in terms of the recognition for the nurse practitioner role; their ability to bill through Medicare—that is quite a thing on its own.

I will highlight, though, that when you have certified RANs (remote area nurses)—we have to do extra courses, there is a lot of pharmacotherapeutics for health professionals that allow us to run by the CARPA guidelines of the PCCN. If you have CARPA and have voluntary assisted dying treatments in the CARPA manual that most NT clinics use, then you will be able to utilise existing RANs because once they have done pharmacotherapeutics they can administer—we cannot say prescribe; we can administer and supply medication via CARPA protocols. That would be one thing I will flag with you guys to look at.

Mr KERLE: I want to raise cultural sensitivity. We are talking about RANs or nurses helping to administer the substance, would there be risks? I know …

NICOLE: To make it clear, I am not talking about the voluntary assisted dying medication; I am talking about medication related to keeping them comfortable before they get

Mr KERLE: Painkillers—okay.

NICOLE: Because it is not like they have volunteered and they are just going to go, ‘Right, today I am going to die’; there will be a build-up to it. They will be extra medication for pain relief and symptom relief and those sorts of things as well. That is where you can look at RANs versus nurse practitioners.

Ms GREER: I would just like to add, for our communities I would in no way recommend any of our clinics hold any medication. I think it needs to come directly from the Health department; it needs to essentially fly-in fly-out from Darwin for any of these, because you have client incidences of youth suicide in communities. We have veterinary drugs that we cannot keep in community, even worming tablets, because they get stolen, even when they are in locked cabinets. Schedule 8 drugs cannot be kept in community. Everything will get broken into. I would never recommend that any of those drugs be kept in community or administered by nurses. I would recommend that it be a fly-in fly-out doctor for situational circumstantial events. Nicky, would you agree?

NICOLE: Absolutely. Nursing staff would be utilised for, like I said, symptom management in the lead-up, but the actual administration—I think Australian law already states it has got to be administered by a doctor in the states that have VAD laws in place at the moment. The actual assisted dying drugs—this is the last hurrah; these are the drugs that are going to end your life—should never be kept in community because of the high incidence of crime, break-ins and youth suicide. It is just too much of a risk.

K McNAMARA: We definitely hear you on that. Part of the recommendations looking at other states is that the idea here or one put forward in the previous report is that it is a centralised model and a whole raft of restrictions around that medication and how that actually gets out to places.

If possible it might help everyone here, some of us and others might not know, if you are able to very briefly explain the differences with your nurse practitioners, ENs, RNs and RNTs in terms of what they can do and what they cannot do in terms of administering certain medications.

NICOLE: Sure. An EN (enrolled nurse) used to be called a division 2 nurse. The EN now does a (inaudible) diploma that allows them to administer medication that has been prescribed. Certainly, probably not in a remote setting, but when you are looking at regional hospitals and places like Darwin. An EN works under the direct supervision of an RN. That supervision can take place remotely, I believe. Best practice is there should be an RN onsite where there are ENs.

A regular RN has full three-year bachelor degree—a registered nurse division 1 in the old language. There is no restriction on their practice in terms of being able to administer medications that have been prescribed by a doctor, as long as that medication is onsite and they follow whatever (inaudible) medication administration now.

Then you have a RAN. A RAN is a nurse that has done courses like REC and MEC, so remote emergency care, maternity emergency care and pharmacotherapeutics. We suture, we plaster, we do lots of—it is a much higher level role. With the pharmacotherapeutic qualification, it allows us to administer or supply medication based on protocol. For instance, in the CARPA manual, if a patient comes into their clinic short of breath, they have got a known diagnosis of COPD and we can clearly see that they are having an exacerbation, we go to CARPA, we look at ‘exacerbation of COPD’, we know that we give them burst therapy of (inaudible) Ventolin. Even though they may not have a valid doctor’s script, the CARPA protocol allows us to give those. It allows us to give 50 mg of prednisone on the spot and provide them with another four days’ worth of 50 mg of pred for the next four days to get them through this exacerbation.

That is an example of the difference between an RN, who would not be able to do that, and a RAN who has done pharmacotherapeutics, who can do that.

The difference between a RAN and a nurse practitioner—nurse practitioners have a much wider scope in terms of medications that they can prescribe and administer. They also have Medicare billing rights, which RANs do not have unless they do it under the umbrella of (inaudible).

Ms GREER: Your standard nurse in a hospital—if I, for example, took my daughter in because she had asthma, in a standard hospital setting, a doctor could see her and provide prednisone. In a remote setting, a RAN could do that. With the absence of a RAN, that child would potentially suffer a fatal asthma attack.

NICOLE: Yes, if you have a RAN (inaudible) then they have access to a DMO service or a telehealth service. It is very difficult. Let me just say that if I was to go back to Melbourne and pick up a shift in the Alfred ICU tomorrow, just because I have done pharmacotherapeutics it does not mean I could go in there and start prescribing and administering medication without a doctor. It has very strict guidelines about when it comes into play. Obviously, that is in remote areas.

Does that answer your question?

K McNAMARA: Thank you. That is so good. I know that these terms have been floated around. I know my mum was a RAN and I have got all the things, but some people might not understand.

Putting that to the side, in a dream scenario of palliative care to come die on country, would you need all those levels? Would you need a nurse practitioner?

NICOLE: No.

K McNAMARA: No—okay.

NICOLE: It probably depends. If they travel as a team. If you have a doctor who is going out there anyway, because a doctor needs to administer these end-stage medications, then you have got have an RN with them. An RN, RAN and nurse practitioner …

K McNAMARA: Different combinations.

NICOLE: … are your three best bets.

K McNAMARA: Okay; thank you.

NICOLE: No disrespect to Ens; I started out as an EN. It is just the scope of practice is a little bit wider in remote settings.

Mr CHAIR: Nicole, you would be aware that the drive within NT Health is to try to procure more ENs at the moment, because RNs are so hard to find, let alone nurse practitioners who are like hen's teeth.

NICOLE: They are.

Mr CHAIR: We are trying to establish what is a workable model. Our goal is not to reinvent the wheel, but to see if we can fine-tune what is recommended from the last report.

On that note, we are pressed for time today. We do not have a huge amount of time to go through all the rest of what we would like to you. It would be enormously helpful if you guys would consider providing us with a written submission after the fact. If you want to go back and have a look at the consultation paper we provided as well, just to provide some of that fine-tuned guidance. It is entirely up to you, of course.

Ms GREER: We absolutely will. There is a lot that needs to be fine-tuned.

As Linda and our aged-care coordinators in the region can attest, we had aged-care services, hospitals, from Darwin asking us to take patients on. In the aged-care sector, for example, under local government, which is where a lot of the aged-care services in the NT sit, under local government award wages. So, our ability to attract the correct people to care for palliative patients, it does not line up—the difference between what is needed for the aged-care sector and what is given under the local government award wage. As you know, in the NT most of the services in aged care, even in remote Indigenous areas, are provided by the councils.

It is slowly becoming direct NDIS services and things that are slowly happening, but, at the moment, the councils are essentially providing these, so they are all on low award wages for local government which does not match up to what is necessary for us to provide those services for the clients. We do not have the funding to provide the level of care that someone needs and, therefore, we have to make sure that there is a clinic manager who will also adjust the rating to be able to provide the level of care, medication and all of the things Nicky said to make sure that person is comfortable, everyday pain medication and things like that. Our health clinics do not have the capability to do that either. They often call us to say, 'Can you administer this medication?' We just say that we are not legally allowed to.

Mr CHAIR: At a high level yesterday, the Department of Health in private testimony also made it clear to us that to provide that service in any form would require additional resources to what we have now in order to administer. The question for us then becomes to hear from people like you about what level of support might be required to meaningfully give effect to VAD laws. It is helpful for us to know the nitty-gritty as well of what you think might work on the ground, based on what the needs are out here.

Ms GREER: Looking at the previous paper, did you want to know what the bare minimum would be?

Mr CHAIR: We are happy to know whatever thoughts you have in relation to bare minimums through to Rolls Royce in the sense that we are neither legal practitioners nor medical specialists. We have a report that got six months of attention with a range of medicos and legal people and all sorts of other people who were involved in the process. That came up with a consolidated view about how we might implement a standalone model in practice. As we are starting to have the hearings, we are teasing out that is still a fairly high-level idea without much clarity about how that might translate.

For example, we know that a single FTE in the Health department is regularly subdivided into multiple divisions; people wear different hats in the Northern Territory. You can say standalone VAD service, but the standalone VAD service must still have practitioners and workforce that have to maintain multiple positions, if you like.

Knowing all the practicalities that you know, anything that you can provide to help guide us will be extremely helpful. On that note …

Ms GREER: I guess for us to—Nicky, you would agree, if we provide them the very bare minimum for it to work would be a good starting place. We do not want to provide 'this is our dream' …

Mr CHAIR: Dreams—sure.

Ms GREER: The very bare minimum is the realistic aspect.

Mr CHAIR: Yes. A pragmatic response would be appreciated of course, because there are lots of people who will either be frustrated that we do not have more time to do the work we are doing or equally be screaming out why are we not doing this faster. We are trying to do the best we can, obviously, within limited time with limited resources.

It has already been extremely instructive today to hear from not only you guys but everybody at Ngukurr who has spoken to us. Anyone who has the time, in fact, even the community people we spoke to earlier today, some of them discussed the idea of putting pen to paper or calling through to our hotline again to give us some further thoughts.

I think of it maybe less as bare minimum and more as what you think in practice as practitioners might be required in order to give effect to that.

NICOLE: Cristie, do you have a copy of the 22 recommendations (inaudible) submission?

Ms GREER: I do not think it was sent through to us from him (inaudible).

NICOLE: Are we able to get a copy of that?

Mr CHAIR: Sure.

Ms WILLIAMS: We can get it through; no worries.

Mr CHAIR: All of that is possible.

We have to wrap things up because we have a plane to catch. Once again, on behalf of all of us, thank you very much for taking the time to speak with us today. This will all be collated and turned into transcripts, as we say, and then we will review those in due course. For now, thank you very much for taking the time, and we hope to be able to progress the issue for Territorians and (inaudible) people like yourselves.

The committee concluded.