The committee convened at 11.55 am.

INQUIRY INTO VOLUNTARY ASSISTED DYING
Julalikari Council Aboriginal Corporation

Mr DEPUTY CHAIR: I respectfully acknowledge the traditional owners of this country and pay my respects to elders past, present and emerging.

My name is Matthew Kerle, I am the Member for Blain and the Deputy Chair, currently the acting Chair, of the committee. This is my colleague.

Mrs CARLSON: Hi, my name is Oly Carlson, Member for Wanguri.

Mr DEPUTY CHAIR: Do you mind if you state your name and title for the record?

Ms FRASER: Mikeely Fraser, I am the Executive Manager of the Child and Family Support Unit at Julalikari.

Mr WILKINS: Lachlan Wilkins, CEO of Julalikari Council Aboriginal Corporation.

Mr DEPUTY CHAIR: Excellent.

We are here to talk today about voluntary assisted dying (VAD), which is the use of a prescribed substance to cause the death of a person who is terminally ill at their request. I can go into talking about what the proposed model for the NT looks like, which is in line with the Australian model which has been legislated in other states and territories. If you would like, I can get into that later in the discussion.

Speaking about VAD may be upsetting. If at any point you feel upset or need support, you can take a break. That is totally fine; people in lots of other of these consultations have done it.

We have been joined by a colleague. Do you want to introduce yourself for the record?

Mr YOUNG: Yes. Dheran Young, Member for Daly.

Mr DEPUTY CHAIR: We plan to record the meeting. The transcript of this recording we would like to publish as part of the parliamentary record. If there is anything that you would like to not be published, please say that and then we can redact it. If you request, we might be able to provide you with the transcript before it is live on the internet and you can highlight any areas that you would specifically like redacted. If you would like that, please make that request.

With all of that out of the way, do you mind just giving us a brief overview of Julalikari for the record? Then we will kick off.

Mr WILKINS: Sure, thank you.

Julalikari has got a very long history, but its core mission is to alleviate poverty and improve wellbeing of Aboriginal people in Tennant Creek and surrounds. That has taken different forms over the years that started as Warumungu Papula Housing Association. We built houses and we have supported people into housing.

In its current form, we have six or seven different business units which is across child and family services. We have got a nursery. We have got a small essential services team. We also have some joint ventures in the BP and IGA with Indigenous Business Australia. We have got an aged-care respite unit as well, which I am hoping a colleague will come and join us because she would have some good perspectives on this particular discussion. That is the broad brush.

Julalikari is a member-based organisation with a board that is entirely Aboriginal led. We have two independent directors that are deliberately from outside the Barkly to provide that transparency and accountability.

I will just add, as I mentioned to you in that discussion before, we have got a community safety patrol division, so we do night patrols and youth patrols as well.

Mr DEPUTY CHAIR: You may not be able to answer this because there might be a board decision. Do you have any comments on whether your organisation or the people you represent would support VAD? If they

do not, if they would be caused harm and suffering if other people who they are not related to—for example, in Darwin—if it was to become a law, if other people did use it?

Mr WILKINS: The way I respond is that, yes, we do not have a settled organisational position, but I would put it, I would be comfortable to say, between the board and our membership—because our membership is quite large—you would have a (inaudible – knocking) of views. I would be surprised if we came up with a consistent view. We would have some that would be agnostic; others would have particularly strong views around it, both as a direct thing but as an order, be that based on religious beliefs or cultural beliefs. I would be very comfortable to say we would not be able …

Mr DEPUTY CHAIR: Diversity of opinions.

Would any of those people, as far as you are aware, personally suffer harm, emotional toll or offence if other people who were not related to them and who were not cultural people chose to use VAD if it were legislated in the NT?

Mr WILKINS: I could not confidently say.

Ms FRASER: I think like Lachie said, they would all have some sort of feeling or views.

Mr DEPUTY CHAIR: Sorry; I realised I missed one thing, so I will back up a little bit.

We as parliamentarians are not here to write legislation. The context is there was an expert report that was written last year requested by the previous government. That was an expert panel convened to look at implementing VAD in the NT and make recommendations. That was chaired by Vicki O'Halloran the former Administrator and Duncan McConnel.

Every other state and territory has legislated VAD. ACT have legislated it and it is pending implementation. They will go live, my understanding is, at the end of this year. After being the first place in Australia to legislate it, we are now the last.

Our remit from the Attorney-General is to basically go and consult remote communities. The feeling was there was not a lot of remote consultation by the expert panel, and being 30% of Territorians, it is pretty important. We are just travelling around and getting the views and input of them.

Now our output will be a report that we will tender to the Attorney-General. That will make recommendations. We are able to reflect some of the evidence that we have received in that report, but what will happen after we submit the report is up to the government. If the committee recommends making legislation for VAD in the NT we would hope that the government would allow that as a conscience vote, but that is a matter for the government.

Do you mind talking a little bit about healthcare, aged care, palliative care? I think you mentioned there was aged care within.

Mr WILKINS: Yes, within our context it is an aged-care respite service, so we do not have people staying over. Some of our clients will come in for a day and that is just as much respite care, so they might come in and they can have a shower. They might live in really tricky conditions on the community living area, so they will come and have a shower and just stay in the air con and get some food. Then we have got a range of other services where we will do a meal delivery service. We also have 10 units that we service. We stop short—we do not administer medication. We do not provide the palliative care; that is then a step up to the …

Mr DEPUTY CHAIR: Is that the PPK?

Mr WILKINS: That is right. That is for intense care; that is the next stage. So we are at that respite support stage prior to any intensive …

Mr DEPUTY CHAIR: They were saying yesterday that they have got a big waiting list of people who want to go in there, but they do not have the capacity. People who are on the waiting list, where do they go at the moment?

Mr WILKINS: I do not know, but I would imagine probably between hospital—some of them, I am speculating, may access some of our services. There are a lot of people, and my understanding is that family and friends

effectively support for free and that is the same in the disability space. So, people will be getting care that just is not recognised or it is not in an institutional setting.

Mrs CARLSON: If someone who is a client or a community member that uses your services does want to go down the line of using VAD, would your organisation help support them through that process? Because sometimes it is not that easy maybe in remote areas to coordinate and access, one, part of the process, but also support them with things like that journey because I think it is going to be quite a difficult journey in coming to terms with. Is that something that you guys would have the capacity to do?

Mr WILKINS: It probably depends on the specifics of what that support looks like. The principal approach I would take is if that is someone's wish then, within the realms of what support we provide, we would try and support them. Like I say, we do not have that direct role in their journey, but if they are our client, then I guess we would support them in the realms of where it is appropriate.

Mrs CARLSON: I suppose the reason why I am asking the question is because we understand that sometimes when people with cultural beliefs and religious beliefs are not going to want to use it possibly, but there can be things like payback and things like that. We are trying to …

Mr DEPUTY CHAIR: Cultural safety.

Mrs CARLSON: Cultural safety for you guys, the community and the workers as well. If you are related to that process, would that affect your core business at all at any stage?

Mr WILKINS: It absolutely could. If someone—if that came up as an issue then, yes, we would sit down with them and the manager of that program, almost on a case-by-case basis, and have that discussion because that broader concept of cultural safety comes up in many different scenarios, and this is a really acute kind of example. I guess to answer that, on a case-by-case basis, we would look at it. Like I say, fortunately, we are in a less—we are in a different situation to PPK where it is a very different relationship. We bring clients in, and it is a respite service. They are genuine concerns that you would need to consider, and you would need to give staff the option, if they were not comfortable, not to be involved in the that.

Mr DEPUTY CHAIR: We have heard evidence in other places that sometimes Indigenous people might have hesitancy in accessing healthcare in a hospital or, say, going to an aged-care facility because there is the perception that it is a place where you die or even they might be killed there because other people die and things. They might be concerned. Do you guys experience any hesitancy accessing the services, or is it well known that you are a place of healing?

Mr WILKINS: Specifically for Julalikari?

Mr DEPUTY CHAIR: Yes.

Mr WILKINS: As far as I am aware, we are seen as a safe place. More broadly, unless you have heard otherwise, most—or at least people I have interacted with—feel comfortable with our healthcare system. There are definitely challenges around death. That can come up from hospital or housing. We spoke to some family this morning who, in a bit of a cultural way, said, 'I should probably leave that house', but of course there are no other houses—just issues like that.

To your direct question, no. My sense of this is we are seen as a safe place.

Mr YOUNG: I do not really have any other questions. I think you have answered most of them.

Mr WILKINS: Pretty well, yes.

Mrs CARLSON: We can probably open it and be broad; is there anything you guys would like to let us know? Are there safeguards and things we should be aware of?

Mr DEPUTY CHAIR: Kinship decision-making if it was legislated or how to keep medical practitioners safe as they are engaging?

Mr WILKINS: I will jump in. If you think of anything, please jump in. I guess there is a broader—we have talked to a few people in the lead-up to this discussion, saying the problem here is not voluntary assisted dying; it is people dying too young from preventable diseases and housing. Not that this is not important, but

people's focus, particularly in the Barkly at the moment, is not access to that; it is access to basic services, housing and education. Add the overlay as well of this is a tricky and challenging subject.

Mr YOUNG: If this was legislated, would you see that as a potential risk of taking resources out of the healthcare system or compromising the healthcare system?

Mr WILKINS: I do not know. It depends a lot on the model. Around that cultural safety piece, again, I am not trying to be bureaucratic, but it is a very tricky one, and medical practitioners would be better placed to answer it. Yeah, there would be—in different contexts, I have heard different things about the way things play out. If you are around or associated with a death, that can have—the bit I am not clear on, though, for that example, I am thinking of was an Aboriginal man who was on a bus when someone passed away. He was therefore associated with that and was concerned for his welfare. I do not know the cultural context and if that is a non-Indigenous doctor in the healthcare system, whether that crosses that a little bit. That is one thing.

Mr DEPUTY CHAIR: In our report, we want to make sure there is cultural safety there because it is probably likely that the majority of people who live on communities will not be interested in VAD. That has been pretty clear.

Mrs CARLSON: We do not think the numbers are going to be high. The trends at the moment—we are the last jurisdiction to have it. We were the first but then we are the last.

Mr WILKINS: I guess it ties back to a state's right to choose …

Mrs CARLSON: The number of people in the Territory could be between 10 and 20 a year. It is highly unlikely that all 20 are going to be from the Barkly region; I do not think that is going to happen.

Mr DEPUTY CHAIR: In pure numbers the expectation is that it will be people from the urban centres.

One of the things that we are interested in, though, is if there are people—we have heard while we have been out bush, people who do have terminal illnesses and, say, end-stage renal failure or they might have advanced stage 4 cancer, and they get to the point where the medication is not working. There were a lot of discussions about finishing up well on country and people wanted to go back to their country and withdraw from care in the knowledge that it will probably lead to their end, by withdrawing from care, but they have had enough. They are sick of the dialysis; they are sick of the medication.

Do you have any experience or have any comments you would like to make about people's ability to withdraw from care and then return to country, wherever country is for them? We heard in Tennant Creek it is here, but if someone has grown up and lived a lot of their time in Ampilatwatja or one of the regional communities that might be home country for them.

Mr WILKINS: Yes, I will just reflect on a personal anecdote. [redacted] The conversation she had was, to your point, they are sick of it. There is an emotional drain and a cultural drain, so first preference was to come back on country and continue renal. She expressed the preference of it is getting to the point where she would sooner come back and basically be on a palliative journey than continue to stay in Tennant Creek or have to go to Alice and be away from your family. It did not get to VAD, but that was, 'That is my preference. I would love to come back and see out my time on country, even if that means I cannot get the care.' But obviously that was not the first preference. They were looking for options.

Mr YOUNG: Did she go down that path, to go back on country? Or did she stay?

Mr WILKINS: No, because for whatever reason that particular (inaudible). I should not name the organisation. It did not happen. I do not know …

Mr DEPUTY CHAIR: For the record if there was an organisation named then we will redact that.

[redacted]

Mr YOUNG: Lack of resources.

Mr WILKINS: Yes, to do renal. As far as I understand, that did not happen. I do not know what the outcome for that family was.

Mr YOUNG: Part of that was the interaction you had with the patient and the family, was it just the one member or were there other family members making that decision around her going back on country to not take dialysis anymore?

Mr WILKINS: In the context of that conversation, I could not tell. With relations, it was her sister but it sounded like the patient herself had enough but still had the capacity to advocate for herself, so as a family they felt like that is what they would have preferred. Again, taken from one family member.

Mr DEPUTY CHAIR: In that context can you comment on how the kinship decision-making, as far as you are aware, would have worked? So that person would have had …

Mr WILKINS: Unfortunately not. She was there just advocating on her sister's behalf, but there may have been opportunistic (inaudible) who just happened to be there. No, I do not have the context of how those decisions …

Mr YOUNG: Can lead to that, yes.

Mr DEPUTY CHAIR: In our report we want to make sure that there is an understanding of and provision for that kinship decision-making. In a dominant culture, Western sort of context, it is an individual choice and they might involve immediate blood family, but in a different context, a community of Indigenous people, it is of a broader understanding.

Mr WILKINS: I know it is not helpful and not definitive, but this is two worlds. What we see in the Barkly is we will have some of the really traditional views of do not use certain elements when someone passes; other people do not mind it. That is why I say there will be such a diversity out there—yes, that mix between individual rights and collective decision-making. Even within families, we will get different approaches, so it is a fraught space.

Mr DEPUTY CHAIR: We are just about out of time. Is there anything you would like to make sure you get on record before we finish?

Mr WILKINS: No, thanks for the opportunity to engage with it. Thank you for coming to the Barkly. I would love to be able to give more definitive answers. We appreciate you taking the time to come down and engage with us. I hope it has been helpful.

Mr DEPUTY CHAIR: Yes.

The committee concluded.
