LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY

15th Assembly

LEGAL AND CONSTITUTIONAL AFFAIRS COMMITTEE

Public Hearing Transcript

11.15 am- 4.00 pm, Tuesday 5 August 2025
Litchfield Room, Level 3, Parliament House

Members:	Dr Tanzil Rahman, Chair, Member for Fong Lim Mr Matthew Kerle, Deputy Chair, Member for Blain Mrs Oly Carlson, Member for Wanguri Mx Kat McNamara, Member for Nightcliff
Witnesses:	***Aboriginal Medial Services Alliance NT*** Dr John Paterson: CEO Ms Tessa Snowdon: Senior Policy Manager
Witnesses:	***Australian Medical Association NT*** Dr John Zorbas: President
Witnesses:	***Private Citizen*** Ms Judy Dent
Witnesses:	***Private Citizen*** Mr Wayne Wood
Witnesses:	***NT Health*** Mr Chris Hosking: Chief Executive NT Health Dr Paul Burgess: Acting Chief Health Officer Dr Jeremy Chin: Chief Medical Officer Dr Kane Vellar: Clinical subject matter expert

The committee convened at 11.15 am.

INQUIRY INTO VOLUNTARY ASSISTED DYING
Aboriginal Medical Services Alliance NT

Mr CHAIR: On behalf of the committee, I welcome everyone to this public hearing for the committee's inquiry into voluntary assisted dying.

Today we will be talking about issues that may be distressing as they relate to death and dying. We acknowledge that these discussions may bring up difficult emotions. If anyone at any time feels upset and needs support, we encourage you to take a break. Support services are also available. Their details are listed on our website and have been circulated here again today at the hearing venue in the attached leaflet. We thank all the participants and observers for engaging respectfully in this important set of conversations.

I welcome to the table to give evidence to the committee Dr John Paterson, CEO of AMSANT, and Ms Tessa Snowdon, Senior Policy Manager. Thank you for coming before the committee. We appreciate you taking the time to speak to the committee and look forward to hearing from you today.

This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. This is a public hearing and is being webcast through the Assembly's website. A transcript will be made for use of the committee and may be put on the committee's website. If at any time during the hearing you are concerned that what you will say should not be made public, you may ask that the committee go into a closed session and take your evidence in private.

Could you please state your name and the capacity in which you are appearing.

Dr PATERSON: Dr John Paterson, Chief Executive Officer for the Aboriginal Medical Services Alliance Northern Territory. I will hand over to Tessa to self-introduce.

Ms SNOWDON: Tessa Snowdon, Policy Research and Advocacy Manager at AMSANT.

Mr CHAIR: Thank you to both of you. Dr Paterson, would you like to make an opening statement?

Dr PATERSON: Thank you, Chair and committee.

I acknowledge that today we are meeting on Larrakia country in Garramilla (Darwin). I pay my respects to elders past, present and emerging and acknowledge that sovereignty was never ceded.

I thank the committee for extending an invitation to the Aboriginal Medical Services Alliance Northern Territory—otherwise known as AMSANT—to appear here today to speak on voluntary assisted dying.

AMSANT is the peak body for Aboriginal community-controlled health services in the Northern Territory. AMSANT has been established for 30 years and has a major policy and advocacy role both within the Northern Territory and at a national level. Our members are located across the Northern Territory from Darwin to the most remote areas. The Aboriginal community-controlled health sector is the largest provider of primary healthcare to Aboriginal people in the Northern Territory and delivers comprehensive primary healthcare in an integrated, holistic, culturally secure framework which combines a population health approach with primary healthcare service delivery.

AMSANT provides guidance and advocacy on a wide range of research, public health issues, education, workforce, continual quality improvement programs, social and emotional wellbeing, housing and other determinants of health that affect Aboriginal people in the Northern Territory. AMSANT has high-level collaborations with the Northern Territory and Commonwealth Governments on these issues.

I acknowledge the work of the voluntary assisted dying expert advisory panel and its role in contributing to progressing this work from August 2023 until May 2024, consulting with communities, individuals and services on complex issues for voluntary assisted dying.

I might, if you are happy, Mr Chairman, refer to voluntary assisted dying as VAD.

Mr CHAIR: Absolutely.

Dr PATERSON: Thank you.

AMSANT recognises the complexity of this topic and that there are diverse views amongst its members and, more broadly, amongst Aboriginal people across the Northern Territory on VAD.

As specified in our original submission to the VAD inquiry in 2024, and as reiterated in our correspondence to the committee in July this year, AMSANT defers to the views of our members and Aboriginal people across the region regarding support or disagreement for VAD as an option to pursue.

In our original submission and subsequently in our additional correspondence, we raised several key issues. These were, and remain:

1. recognition of the diversity of perspectives amongst Aboriginal and Torres Strait Islander peoples

2. concern that the absence of equitable access to high-quality palliative care undermines the capacity of genuine choice

3. the need for robust cultural governance structures and the inclusion of non-clinical perspectives in any future legislative or service design processes.

AMSANT's position remains unchanged. We do not hold a singular position for or against the legislation or VAD. Our role is to support our members and advocate for culturally safe, equitable and community-led health systems. In saying this, we feel it is pertinent to express our disappointment in the format in which additional consultations led by this committee have sought to be conducted. AMSANT has consistently advocated for the need for well-resourced, culturally safe consultation processes, particularly when engaging Aboriginal communities on complex issues, such as VAD.

While we acknowledge the committee's stated intention to consult across the Northern Territory, we are concerned that the timeline and resourcing allocated does not reflect the scale or cultural complexities of this task. Consultation in a remote Aboriginal context requires more than routine outreach; it demands cultural competence, establishment of trusted relationships and considerable time investment. Discussions involving life, death and care at the end of life intersect deeply with cultural and spiritual protocols. These factors must be central to any consultation approach.

The 2024 VAD final report identified specific concerns raised by some Aboriginal Territorians and emphasised the importance of trauma-informed care, cultural safety and the diversity of Aboriginal and Torres Strait Islander views. These considerations must be integral design principles for any further engagement or policy development and must not be treated as procedural box ticking if it were to be pursued post the completion and publication of the 2024 report.

Additionally, in communities where English is not the first language and health literacy is shaped by diverse lived experience and histories, the risk of misinterpretation is high. Without adequate preparation and facilitation, there is a risk that the consultations will inadvertently re-traumatise communities or lead to community disengagement or loss of confidence in the process.

Ultimately, if further consultations will proceed that will contribute to outcomes pertaining to VAD and its implementation in the Northern Territory, consultation frameworks will be informed by:

- Aboriginal peak bodies and Aboriginal community-controlled organisations with relevant expertise

- culturally credible facilitators who have established community relationships and appropriate language proficiency

- the process be resourced appropriately with a realistic timeline that allows for genuine engagement

- the emphasis shift from engaging support or opposition to a shared understanding and to hear the stories that matter.

We are not confident that such processes are currently in place and meeting this standard will require a significant shift in approach to community consultations. In its current form and in reflection of the process, AMSANT cannot voice or support the model of consultation being pursued by the committee.

Mr CHAIR: Ms Snowdon, would you care to make an opening statement?

Ms SNOWDON: No. The opening statement that Dr Paterson gave was on behalf of our organisation, thanks.

Mr CHAIR: Dr Paterson, thank you very much for your thoughts. We note that this is a time-limited process. The committee, internally, has also recognised that it is a very short timeframe in which to do the work that we have been tasked to do. We are trying in earnest to do the best we can within the parameters of the inquiry terms of reference that we have been provided. We have a shared commitment to engaging in a respectful and culturally appropriate process in so far as that is possible.

With that in mind, there is a number of practical things in relation to the 2024 report in particular that we would like to seek your thoughts on, if that is okay. I note for example that you reflected on equity in health systems and palliative care—these are things that you can provide us a unique perspective on.

Within our consultation paper we are broadly seeking to interrogate the 22 recommendations of the independent expert advisory committee and those fall across, if you like, implementing VAD in the Territory, eligibility, the VAD process and then oversight and review.

I might start off by asking you about one of the core components of the 2024 report, which was a recommendation to create a standalone centralised model of service delivery separate from NT Health. What are AMSANT's views on the merits or otherwise of that proposal?

Dr PATERSON: I might just get opening responses from Tessa and then I can add if she misses some of the things.

Ms SNOWDON: It is worth us reiterating that the position we have come here today is to not speak to those specific recommendations. We have made clear in our correspondence and our opening statement and, more broadly, the structure of systems that are going towards these inquiries. From AMSANT's perspective we have not changed our position from the 2024 submission which included the need for significant increase in resourcing, more robust engagement, a social cultural approach to the design and governance of that and the choice of services and clinicians.

In terms of that last question around the centralised body, our position remains the same, that any legislation enabling VAD in the NT should not mandate primary healthcare services and individual clinicians to participate in VAD. Services and individual clinicians should be given the option not to participate which is in place in other jurisdictions.

We have not had the opportunity to consult broadly with our members on the very specific recommendations and, to be quite frank, the consultation paper with its very broad questions and the short timeframe we were provided with here today have not allowed for us to undergo that consultation. We would be interested if there was a more substantive process that was going to offer something different to the process outside of just looking at that report from 2024 and progressing the work or not progressing the work with more clear parameters to figure out how we could support that across our membership in the Northern Territory. Currently, as Dr Paterson stated in our opening statement, we have not seen within the terms of reference of this committee or the work being carried out a commitment to meaningfully engaging with people in communities in a culturally safe manner.

Mr CHAIR: Dr Paterson, did you want to address the question specifically?

Dr PATERSON: No additional comments.

K McNAMARA: Thank you for your opening statements. There have been discussions, and members of this committee have heard loud and clear some of your concerns. I am just thinking about changing some of the questions to take on board some of that information that you have said.

I understand you said you have not had time to consult properly and appropriately with your members. Are you able to say what role AMSANT could play in supporting culturally safe access to VAD if it is adopted in the NT?

Ms SNOWDON: I am probably going to sound quite repetitive through this evidence.

AMSANT is a peak body, and we are made up of member services. I note that, for example, one of our members has provided a submission that is published on the website for this inquiry. They reiterate that position that there are diverse views, people need to be engaged meaningfully. If AMSANT's membership did determine and communities did determine support, we would definitely be able to play a role determined by our membership into the future and dependent on the structure that exists at that time. It is not for us to predetermine what that could look like without that engagement.

Dr PATERSON: I might just reinforce that AMSANT would not see it as our responsibility or part of our core services to manage or make decisions on behalf of our members. As you are all aware, this is a very sensitive and cultural issue for the more remote you go—amongst the Aboriginal population in the Northern Territory, generally speaking.

In consultations I had with community leaders on this particular topic it is fairly short; they do not want to discuss it because they have their own cultural protocols back in their communities about the end-of-life process. As Tess said, I think those decisions need to be made at that community level.

I am not sure whether the committee is exploring what sorts of support programs or services can be provided to those remote communities that may seek from governments. I am not sure what those support services and programs might look like or entail.

I think back to our earlier comments, there needs to be as much as possible—Chairman, I heard you this morning with your comments on ABC radio, making those comments that it is challenging to have those consultations, more broadly, throughout remote Northern Territory. In every effort—given the sensitivities around the short list—there need to be very sensitive and respectful processes undertaken.

Mr KERLE: Thank you, Dr Paterson, for coming today. We appreciate you coming to assist us with this inquiry.

We have been talking about the cultural protocols that need to be respected. You have long experience working in Indigenous communities. Are you aware, do you have any recommendations on any culturally specific safeguards that you believe would be essential to ensure informed and voluntary decisions in Aboriginal communities if this legislation were to go ahead? How could people on communities be respected and safeguards put in place so that they would not feel obliged in any way regarding this topic?

Dr PATERSON: Good question, Mr Kerle. This is a personal view. The legislation needs to be as flexible as possible, not one size fits all. As you would be aware, Aboriginal communities across the Northern Territory have different spiritual cultural responsibilities and protocols.

In terms of the legislation it needs to recognise that those decisions need to be made locally. That is why AMSANT's position is not either supporting or not supporting this legislation. That is part of this process that we believe needs to be undertaken—more extensive consultation before. That will be one of the questions for the community that needs to be asked and tested with remote communities more respectfully throughout this process.

I will leave it there. Tess, do you have anything extra to add?

Ms SNOWDON: No. I think that point you have made, Dr Paterson, on the fact that Aboriginal communities and culture are not homogenous; people have varied views and belief systems.

A lot of the high-level cultural complexity issues relevant to that are captured pretty effectively with appendix 9 of the final report from 2024, where the cultural protocols and that need to have that nuance and varied understanding and a quite resource-intensive approach to working with people on communities. If the legislation was to be introduced or adopted that it is set out quite thoroughly. I think that kind of work in addition to the information we have provided today and previously provides a pretty strong standpoint for the kind of thing that would need to be undertaken if this legislation was going to progress, regardless of what consultations occur beforehand. It is on page 126 if you are having a little squiz.

Mr CHAIR: Thank you for that refresher on the page number.

Mrs CARLSON: I understand there are some complexities with Aboriginal and Torres Strait Islander peoples involved with this VAD inquiry and in past with beliefs and cultural standings, but do you think there could possibly be a way where someone or a group of Aboriginal or Torres Strait Islander people could be involved in still designing if it is to go ahead, in a respectful manner obviously. It would be important to still have those conversations. I know you mentioned before that trust needs to be built. If trust cannot be built, how do we overcome still being able to work with those people?

Dr PATERSON: There could well be communities that might be prepared to give advice and be consulted thoroughly in this process. I think another good potential source of seeking the views of Aboriginal people in the lifespan process would be those—I am aware there are a couple and not a great deal of Aboriginal people working in the palliative care sector at various hospitals throughout the Northern Territory. I wonder whether that would be a good source of seeking their counsel and views as to whether those—I am thinking more remote Aboriginal Territorians who may be in those hospices and in palliative care as part of the end of their lifespan who may want to share experiences. I am not sure what sorts of conversations have been had apart from families that are obviously spending the last valued time with their loved ones and find themselves in that situation. I am not aware, unless Tess had some other research and found some other information about Aboriginal communities throughout the Northern Territory that would be willing to participate and have more further discussion about this, particularly the pros and cons about VAD.

I heard I think this morning on radio where—Chair, you may recall who that conversation was with—I think there was some mention about a 12-month versus six-month time period if somebody had an acute or severe life-ending disease. I cannot recall what the two periods were now. I think those sorts of things and everything should be looked at and put on the table for consideration.

Tess, are you aware with your research, any communities, apart from the one you acknowledged, that made a written submission online or any other views around that?

Ms SNOWDON: From conversations I have had broadly across our membership and with other Aboriginal community-controlled organisations across the region in this space, because some of the lack of clarity around the direction of where this work is going after the report has been handed down, it is hard to consult in community or to utilise relationships without a clear purpose behind that and how to align it with things like the priority reforms on Closing the Gap and shared decision-making, and components like that, that a lot of the organisations work under and towards.

There is a broad recognition across our membership and the broader sector that this is a really complex and varied issue. There would be a willingness to engage by these services if there were clearer parameters around what we were actually engaging on and the outcome of that—within a piece of legislation, for example, or progressing work separate to that. That would probably help organisations that can help facilitate that engagement to understand what they are seeking engagement on and be able to define their core business separate to that of the inquiry or consultation that is occurring.

Mr CHAIR: Ms Snowdon, this is a discrete piece of work that does not currently have a direct intersection with a lot of those things that you have spoken about. For our purposes, we have been tasked with specifically inquiring into the 2024 report to try and progress the issue of VAD in the Northern Territory.

There is not a Bill to consult on at this stage. If our process ends up suggesting that there should be legislation in this space, we will generate a report with drafting instructions for what that Bill might look like. The scope of that Bill would be based in and around, by default, the 2024 report. We are trying to attenuate what is in that report to make sure that it is appropriate because there was the suggestion that people in Indigenous communities, particularly remote Indigenous communities, had not been adequately consulted.

I take your point that it is time limited. We are not getting to do six months of exhaustive consultation. In saying that, it is extremely helpful for us when we get reflections like, for example, noting that you see value in appendix 9 of the 2024 report. That is a very helpful, guiding instructive thing for us.

It is process that I am interested in, in that regard as well. We are trying to shift the agenda forward. There is a wide recognition by everyone on this committee that Indigenous communities are not homogenous. We have tried to get a representative geographic spread across the Territory within the timeframe we have, using a hub-and-spoke model. We will not be able to cover the field on everyone. At the moment, we are optimistic about the fact that many more communities have said yes and would like to be involved, than the handful that have indicated that now is not an appropriate time and/or they are not clear on parameters.

To clarify, for us, the parameters are very much interrogating the 2024 report. What could we do to implement what has been suggested in the 2024 report in a manner that would be suitable for the Northern Territory and suitable also for people in the remote Indigenous Territory?

I take all the caveats on point, but can you identify anything from the 2024 report that stands out to you as ‘that is a sensible direction to pursue’ or ‘that is a red flag for us and not a direction we want to go in’—the 12-month, six-month timeframe, for example? This kind of fine grain detail stuff is what we will need to consider line by line in trying to provide guidance for a model piece of legislation. Any specific thoughts?

Ms SNOWDON: Using appendix 9 and those considerations put forward to base further consultation and dialogue with remote communities will be a very helpful tool because it provides that contextual understanding of those variabilities. It also provides more context to previous conversations that have already occurred, so you are not going in with the report and saying to people, 'Now there is a bigger report. Can you talk to us about how you feel about it?' It gives a basis to begin those conversations.

I apologise. I have not seen this online, but in terms of also having resources translated into language and maybe having that appendix translated into language so that when you are visiting various communities, people have the option to engage as well in a language other than English could be helpful, and expanding the resources available so that in preparation for any visits that the committee will make to community—I note that there is a number listed on the inquiry's website—having those resources and guides in the hands of community members early they can have the relevant conversations with their community leaders, families and service providers, whoever it is, in anticipation of engaging with the committee.

K McNAMARA: I am curious to go back to the statements and some of the issues you raised about the cultural complexities. Obviously knowing the timeframe, in an optimal world, how would you see consultation roll our in a way that would be the most appropriate way?

Ms SNOWDON: Sorry, is that question for me or …

K McNAMARA: To anyone. I am trying to tease out some of the things you raised in your opening statement.

Ms SNOWDON: Patto, do you want to take that one first?

Dr PATERSON: Our communities are busy communities. We have to plan and look at well in advance—12 months in advance for various meetings in light of AMSANT's core business—for general meetings where we get all the members into a location for discussion on a number of health and wellbeing issues about which we want to seek their counsel, views, opinions and ideas on.

It has been acknowledged by both sides that the timeframe is too short. Realistically, you have to give them as much advance notification. Then it is the language barriers; making sure that people are available—preferably the services of the Aboriginal Interpreter Service. I add that the Northern Territory remote Aboriginal investment—I think we have increased the funding allocation for those services to be more expanded and cover these sorts of important legislative and policy issues that Aboriginal communities are facing from time to time.

We have the Wet Season and Dry Season that brings their own pros and cons; mainly in the Dry Season a lot of ceremony is happening. That is why it is really difficult to get some of those meetings held with relevant communities in the Northern Territory. In the Wet Season there is the issue of travelling and people not being available.

People are busy; they have communities to run. Hence, my advice to the committee and for any parliamentary committee is that you need to plan well in advance. If we do not consult and get the due time and processes, then it makes it difficult for pieces of legislation be considered in a timely and respectful manner, I believe.

K McNAMARA: Some of the other questions I have are more technical and practical in nature. I heard you say that you have not had time to consult with the rest of the membership of the peak body, and I do not want to dump questions.

Mr CHAIR: That is perfectly fair. We all appreciate that we are doing something in a time-limited time. It is important to reiterate that if and when there is a Bill in relation to VAD in the Northern Territory, then there will be—one would imagine—exhaustive consultations with individual organisations, members of parliament and so on and so forth will have to do on that Bill.

The question is whether we ever get to a Bill. We are trying to tease out whether or not we can help provide any better guidance than what is contained in the 2024 report, given we have been given the opportunity to do so.

On that note—if you do not mind, I will jump in again—your core business is obviously not voluntary assisted dying. We are interested in your thoughts on the palliative care system and the interactions between that, potentially, and a standalone VAD service were it to be available. This is some of the fine grain detail that has not been really prosecuted or thought through.

I am rephrasing my existing question, but knowing the limitations within the healthcare system, does our healthcare system have the capacity to offer a standalone VAD system in parallel with palliative care and primary healthcare services? Do you have a view on that individually or organisationally?

Dr PATERSON: Sure. We find it challenging, Chairman, to deliver, particularly allied health and specialist care such as VAD, for example, to remote communities. The more remote you go, the more challenging it becomes due to workforce, infrastructure capacity, cost of delivering those services—when I talk about workforce, getting doctors and nurses to commit to residing in those communities. The bigger ones we find them a little more acceptable, given that they sometimes have discrete and dedicated housing for clinicians for their workforce. Generally speaking, it is a real strain. We have acknowledged that across the Northern Territory housing and accommodation is still on the priority list and a lot more work is to be done there.

In terms of the future model of primary healthcare services in the Northern Territory, we want to work with those standalone communities. You would be well aware that there is a policy reform that is happening in the Northern Territory with transitioning Northern Territory Government-run clinics—those who want it—across to Aboriginal community control. We are looking at modelling them off successful models and regional health providers like Miwatj, Katherine West, Sunrise and Congress. The Aboriginal Congress in Alice Springs is in the process of transitioning a number of Northern Territory Government clinics under their auspicing until those remote communities decide, at a cluster level, about whether they want to be incorporated and have their own health boards that make local decisions, as they see fit, for health and wellbeing services in their communities.

We are trying, as best as we possibly can. This ain’t going to happen overnight; this is a long process. Red Lily Health Service, which has just signed the transition agreement for the Gunbalanya clinic, Oenpelli, across to Red Lily Health Service to manage and be responsible for delivering primary healthcare services to the residents of Gunbalanya. That footprint also includes Warruwi, Minjilang and outstations and other communities within the Cobourg Peninsula region, the Jabiru residents and the Kakadu homelands.

They are the sorts of models for economies of scale, a whole number of reasons, that we have as a policy position under the Northern Territory Aboriginal Health Forum, where we can no longer fund into the—not fund. Those standalone clinics will remain, as best as they possibly can, but our agenda and reform policies are to get them to work with nearby communities within their footprint area, so we can get those economies of scale and address workforce issues et cetera, and get a hub-and-spoke model of service for the allied health and specialists, which again is difficult to get to remote communities. The bulk of the time there is no other option but to bring those patients into Alice Springs, Katherine or Darwin for that acute care.

We are trying our best working with the Northern Territory Government’s Department of Health to look how best we can get a more collaborative, strong, if you like, or hub-and-spoke model that can at least pick up and cater for some of those acute and allied health specialists services out of Darwin because there is a perception amongst the remote communities—and you guys would have heard it—that once countrymen leave community and are in need of acute care, they go off on that plane, and the next time they come back is in a box.

If we use that scenario, how can we best put in place a program or process where loved ones can spend as much time with patients who have those terrible diseases that we know in the Northern Territory, so they can spend that last quality time with their loved ones, as close to home as possible, rather than them all coming in. This is where the pressure comes into the bigger cities and towns when family members come in for healthcare, and next thing the families want to come in—and rightly so—to be with their loved ones while they are attending the acute care in our regional hospitals.

That is a challenge for all of us. How do we best try to get some of those services closer to community. We will never get them in every community, and that is why a hub-and-spoke model would work with those larger regional communities that might have the capacity and the resources to be able to cope with that and deliver those sorts of services.

Mr CHAIR: That is a very detailed statement without ever saying the words ‘palliative care’ I noticed.

Dr PATERSON: Yes, and palliative care is one of them. I mean it would be great to have palliative care based in Maningrida or Wadeye. Correct me if I am wrong, but has Nhulunbuy got a facility there? I am assuming they would.

Mrs CARLSON: They have a special room built into the corner of the hospital when it happens so that they can come culturally and respectfully say their goodbyes. They have considered that, so hopefully they expand on things like that.

Mr KERLE: Dr Paterson, thank you for your contributions; we really appreciate that. I have a question that is a little bit sensitive, so feel free if you think it is not appropriate to answer, please say that. Having spent a lifetime and a career working around Indigenous communities, to inform the committee, are you aware of any practices that Indigenous people had prior to western contact regarding when old people got sick and could no longer keep up with the group as they were moving around the country—so we are informed on any pre-existing practices that may fit into the same slot we are discussing here. Are you aware of any such practices? Please feel free if this is not appropriate not to answer.

Dr PATERSON: The short answer is I am not privy to it personally. That is that real sensitivity and cultural activity that is fairly close to community, and given the sensitivity of it all, those practices are not widely known. I am not in a position to comment on that. It is one for communities to take onboard and respond to. Tess, did you want to add anything there?

Ms SNOWDON: No, nothing from me. I am a non-Indigenous person, so I cannot really speak on cultural protocols. I think it is important that as non-Indigenous people we recognise the cultural sensitivity of questions like that. Certain levels of cultural protocols we will never know, and people will not feel comfortable sharing them with western systems, and we need to recognise that. I think that has been done.

Mr CHAIR: Dr Paterson, Ms Snowdon, I am afraid we are short on time and have a long day of hearings ahead of us. Before we let you go, I want to check. Your letter of 28 July that you provided us is quite instructive. Would you be willing to let us publish that as a submission, as part of the inquiry? It is entirely up to you.

Dr PATERSON: Seeking advice …

Ms SNOWDON: Yes, that is fine to be published. We have already shared it with our membership, so that is fine.

Mr CHAIR: It is a helpful contribution, which is why I am asking now before we have even got to talking about it later in the day.

Ms SNOWDON: Sorry, Chair; I think it would also be helpful if we could request as an addendum to that our 2024 submission which was published, because we refer to that in the letter. I know that we did not, from memory, resupply that submission with the correspondence. If it is possible to request that is put together, that would be great.

Mr CHAIR: I am sure that would be fine.

Thank you very much for making yourselves available today. Processes like this have much more integrity, in spite of their limitations, when we are able to hear from all of the important stakeholders. You are obviously a critical stakeholder in this conversation. We very much appreciate you making the time to speak with us today in person and via Teams.

This will not be the end of the conversation on VAD. We are all aware of that. What we are hoping to do, as a committee, in a cooperative way is to progress the issue and conversation respectfully and in an appropriate manner for all Territorians.

Thank you once again for your time. We look forward to speaking with you again.

Dr PATERSON: Thank you, Chair and committee.

The committee suspended.

Australian Medical Association NT

Mr CHAIR: Dr Zorbas, on behalf of the committee, thank you very much for coming to this public hearing today about the committee's inquiry into voluntary assisted dying. We will be talking about issues that are distressing to many as they relate to death and dying. We acknowledge that these discussions bring up difficult emotions for some people. For you, as much as anyone else in the room or who might come in, if at any time you feel upset or need support, we encourage people to take a break. We have support services available and details are listed on the website as well as circulated around the table. We thank you for participating today. We ask everyone who is in the room to engage respectfully in these important conversations.

I welcome to the table to give evidence to the committee Dr John Zorbas, President of the Australian Medical Association NT. Thank you for coming before the committee. We appreciate you taking the time to talk to us. We look forward to hearing from you today.

This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. This is a public hearing and is being webcast through the Assembly website. A transcript will be made for use of the committee and may be put on the committee's website at a subsequent time. If at any time during the hearing you are concerned about anything you want to say which should not be made public, you may ask that the committee go into closed session and we will take your evidence in private.

Could you please state your name and the capacity in which you are appearing.

Dr ZORBAS: Dr John Zorbas. I am here as the President of the Australian Medical Association Northern Territory Branch.

Mr CHAIR: Thank you very much, Dr Zorbas. Would you like to make an opening statement?

Dr ZORBAS: I will keep my opening statement short. In brief, there are four questions that have been presented in the inquiry, the first and foremost being whether we support making VAD legal in the NT.

The Australian Medical Association has a revised position statement—it is now our second position statement—on voluntary assisted dying, which was revised earlier this year. Ultimately, our position can be condensed down to four main statements. Ultimately, we support the introduction of VAD legislation in the Northern Territory under the principle of equity of access to healthcare. We are the only jurisdiction left in the country in which it is not available. Whilst ACT is not online yet, legislation has been passed.

The AMA has respect for divergent views in this space amongst our member base as well. There are practitioners who hold opposing views on the introduction of VAD legislation in the Northern Territory. We support legislation that supports the principle of equity of access to healthcare. Ultimately, that puts us in a position where we must support VAD.

Under that heading, it is important that palliative care is kept paramount as a consideration. VAD should not be introduced to the threat or exclusion of palliative care resourcing. There needs to be clear separation between palliative care and VAD services initially. While that may change over time, it is the clear position of our palliative care physicians in the Northern Territory that there needs to be a separation of those two services to allow both services to function.

Telehealth will be essential to the provision of safe and equitable access to VAD in the Northern Territory, more so here than anywhere else in the country. That is problematic, given that it is currently a criminal offence to provide assistance with death and dying over a carriage service. That is a hurdle that needs to be crossed from a legislative point of view.

Finally, there needs to be a robust legal framework for VAD legislation, of which I can go into more detail with the questions that have been provided by the inquiry.

Mr CHAIR: Dr Zorbas, thank you very much for those remarks—succinct, to the point and helpful for us because we want to get under the hood and into the nooks and crannies.

As you will be aware, we have been tasked with conducting an inquiry on a specific remit. The focus point is the 2024 independent expert panel report and the 22 recommendations contained therein. We are keen to see if we can attenuate any of that, improve upon it, particularly learn anything via remote consultation.

As you alluded to, telehealth may play a part in VAD going forward. It is currently prohibited under federal law. Can you see a standalone service, as recommended in the expert report, being enough to be able to provide equitable access to VAD, independent of a telehealth solution, or can this simply not work without telehealth?

Dr ZORBAS: A viable service could be presented and supported without telehealth. It will make it more difficult, more resource intensive; it would not make it less safe if there are safeguards about the way it is administered.

Mr CHAIR: What might some of those safeguards look like?

Dr ZORBAS: Other jurisdictions have a minimum of two consultations by a suitably qualified medical professional to decide around VAD eligibility and access to VAD. Ideally, if one of those was to be done over telehealth, that would help equity of access. If telehealth was not available, that would commit us to having to do two face-to-face in-person consultations. With that comes the cost of transport, given the fly-in fly-out nature of what is likely to be a centralised VAD service in the Northern Territory. There is a cost associated with that. That will lead to delays. When we are talking about issues like access to voluntary assisted dying prior to death from a terminal condition, those delays will push some people past the ability to use VAD and to access VAD. Whilst it might not lead to an unsafe service, it will lead to a less effective and a less quality-focused service.

Mr CHAIR: We are, of course, trading in hypotheticals to a large extent. Were there to be a VAD model implemented for the Northern Territory at some point in the future, could you envisage a standalone service which was able to provide, via telehealth consultative services, but that any final part of that operation might be an in-person service. Is that what you would envisage might be practicable?

Dr ZORBAS: Yes, at some level it must be face-to-face. Something like VAD is not currently done around Australia purely remotely. While that is theoretically possible, we would support face-to-face where feasible, where required and have minimum levels there as well. As I said, if there were two consultations, at least one should be face-to-face.

K McNAMARA: What are the AMA's thoughts about the 12-month prognosis—in some states it is six or 12, if it is cancer versus other diagnoses? Have you got any thoughts about that in terms of the threshold for accessing voluntary assisted dying?

Dr ZORBAS: We have no formal position in the AMA NT on whether six or 12 months is more appropriate. In the absence of that formal position, recognising that prognosis can be tricky and variable, we would err on the side of caution as a general principle and suggest that 12 months is a wider window and gives people more time to plan, more time to access, more time to discuss with their family, friends and loved ones and plan how they would use access to that.

There is no medical or scientific reason for differentiation between six and 12 months. It is purely the framework set up by the service and how resourced it is, how effective and efficient it is, would determine whether six months is viable or not. If a service was set up and was not resourced appropriately, and especially here where remote and a lot of travel will be an aspect of this theoretically, six months may be too short.

In the absence of a formal position, we would favour 12 months.

Mrs CARLSON: Tying in with the Member for Nightcliff's question regarding timeframes, is it likely the word 'suffering' needs to be defined to maybe determine some of those timeframes because of people's pain thresholds or even just their readiness in having the option to end of life? How do we define suffering or is that going to be a critical term that needs to be redefined?

Dr ZORBAS: I know in previous submissions much as been made of the definition of what suffering is. Suffering is ultimately something experienced by the individual and not by the system. It is very difficult to come to a medical definition of what suffering is.

From our perspective, I think the definition of suffering is, to be very specific around that definition in a medical sense, less important than appropriate resourcing of services that will alleviate suffering, hence the importance to resource palliative care appropriately and make sure that people have access in all the end-of-life decisions that one might make, and the spectrum of what that means—advance care directives, palliative care, VAD.

It is important that people have all the information available to them and understand that information so that they can judge their own situation appropriately. If suffering is being experienced because of a misunderstanding of what is available to an individual, that is a difficult situation to be in, and a definition of suffering will not necessarily change that, but appropriately resourcing of those services will.

We recognise that there is a shortage of access to psychology services in the space of palliative care. We are very short on psychology full-time equivalent staffing and the same would be true for any VAD model. It is very important that we have appropriate access to psychological services to allow people the time, space and expertise to explore their suffering and what that suffering means to them and how they plan to deal with that suffering and what is available to them.

Mr KERLE: Earlier today Dr John Paterson from AMSANT testified about some of the sensitivities involved with our unique cultural circumstances. Do you have any perspective on safeguards that could be implemented in a potential future VAD program in the Northern Territory for Indigenous communities in terms of not impinging on their likelihood to access health? For example, he gave a story about people who have serious medical illnesses and leave the community to go to town to receive medical treatment. Sadly they pass away and come home in a box, as he said. We are very sensitive that we do not want any potential VAD program to dissuade people in community from accessing healthcare. What kind of safeguards could guard against that?

Dr ZORBAS: Our palliative care physicians have emphasised that they want to see a separation of VAD services from palliative care services. This is not because they do not want to run, control or be part of VAD services. There are palliative physicians that do want to be involved in VAD and those who do not. It mostly is to differentiate to any member of the public who is looking to access VAD or palliative care that they are two different services with two very different foci.

It is difficult enough to deliver culturally safe communication in our current model of healthcare, as I am sure you all know. The concept of individual autonomy, terminal illness and dying is hard enough in your native language and your own culture, let alone somebody else's. It is a difficulty we face on a daily basis in our health services. That is amplified in the VAD space. To that end, separation of the two services is essential to that initial safeguard. That is not to say that it might not change over time, but it is certainly how it should begin.

Any VAD model should be co-designed with our Indigenous communities, drawing on the experience of the Aboriginal medical services, bodies like AMSANT's expertise in this area, the land councils, community elders. The diversity of community and culture across the NT is incredibly high compared to other states and territories in Australia. There will not be a one-size-fits-all model when it comes to questions of culture and death and dying across the Territory.

There is a huge importance on the use and the appropriate resourcing of interpreters. A lot of healthcare is done in language and a lot of it is not done in language. This is a space you have to be 100% certain that the decisions that are being made are being understood and the capacity is an essential component of this. Where interpreters are required, people must have access to those interpreters who must be appropriately trained. There are some concepts in VAD that do not have terminology in other languages, not just speaking to Indigenous culture but also other cultures that we have in the NT. Those interpreters will need to have formal training in that space as well.

To that end on the question of training, that also applies to medical practitioners, nurses, pharmacists, lawyers and any other expert involved in the delivery and design of the service. There is very specific training that is used in other jurisdictions around VAD concepts and VAD delivery mechanisms that serve to safeguard the service itself.

Mr CHAIR: As you will be aware, this inquiry is designed to supplement, not supplant, all the prior work that has been done in this space. We are looking to fine-tune what is in the 2024 report, in so far as we can, based on the feedback we were able to gather from remote consultations, in particular, but also by checking in with best practice at this point in time, noting where other jurisdictions are up to.

You have already alluded to capacity deficits in workforce in NT Health. That is a known fact. I am getting right to the crux of the issue here. Do we have the capacity, from your perspective as the representative from the AMA, to be able to provide a VAD service in the foreseeable future, under the guise of the 2024 inquiry model?

Dr ZORBAS: Yes. It would require resourcing, dedicated recruitment and retention. We could deliver the service if we needed to.

Capacity is an issue and has always been an issue for my entire career. That by itself is not enough of a reason to deny equity of access to healthcare, as long as we continue to adhere to the principles of safety and equity.

Mr CHAIR: On the same note, we know that extrapolating reasonably from data elsewhere what probable numbers might be of uptake of VAD, within a certain a tolerance. It is not huge numbers. We are talking about setting up what might be a very complex, challenging service for potentially very few people. Is it still the case that we warrant having a standalone service or is this a service that we could effectively outsource from another jurisdiction? We are trying to establish whether the Northern Territory requires a standalone model of its own.

Dr ZORBAS: It is possible to outsource it. One of the perverse benefits of being the last jurisdiction is that we have a lot to draw on from the other jurisdictions and the challenges they faced. Having said that, something that is so closely and intimately linked to the Territory and the lifestyle that people have here, the rurality and remoteness of the jurisdiction could only be understood by those who work here. An outsourced service presents risks if the designers and operators of the service do not live here and understand the Territory. We see this on a daily basis with doctors who come to the NT having never worked here before. There are stark challenges they face on day one that take weeks, months and years to comprehend and understand.

We favour a standalone service. An outsourced service could still be delivered; a standalone service would be preferable.

K McNAMARA: On the topic I think you mentioned before palliative care. Obviously, the concern is raised about we do not want this to take away from palliative care. Are you able to expand or speak more broadly on the current state of palliative care and how you see a standalone model interacting with current palliative care?

Dr ZORBAS: Yes. I would have to take questions on notice as to specific questions on FTE and staffing. I will say the experience in other jurisdictions have shown that when you introduce a VAD service you increase the workload of palliative care services. As people start to explore their end-of-life options, that increases health literacy, knowledge and access to the services, so we see an uptake in those seeking palliative care. That, in itself, requires increasing resourcing.

Palliative care physicians are the experts of end-of-life care. From a medical standpoint they are the craft group we go to as the stand-up experts on end-of-life care. That is not to say that it is the only the domain of palliative care physicians, but a VAD service needs to be designed with the input and guidance of palliative care physicians, given that this is their area of medical care and they are the experts on what good end-of-life care looks like and the essentials of good end-of-life care, especially the cultural and spiritual concerns which other doctors may not have had as much experience in.

K McNAMARA: In terms of the training and resourcing needed, would it be mostly palliative care specialists who are perhaps also involved in voluntary assisted dying? What other specific training is there for non-palliative care people to enter that space?

Dr ZORBAS: Across the country, some doctors involved in VAD are palliative care trained, and some are not palliative care trained. A training package would have to be developed for an NT standalone system, if only to make sure we address specific Northern Territory concerns on top of the education and training that would be needed to deliver a VAD service, and the mechanics of that.

That training package would need the input, guidance and design of palliative care physicians. That would also include palliative care nursing staff, lawyers and legal advice in this space, and pharmacists who have been involved with that prior to this. It is quite a broad and multidisciplinary training program/

Mr KERLE: This is a question probably more for the record than anything else. I am not an expert in the different levels of accreditation that doctors have. I am aware that there are like apprenticeships, then registrars. Does the AMA have a position on what level of attainment would be required for a doctor to be recognised to be one of those two consulting physicians in the VAD process?

Obviously, someone who is first out of uni can start to prescribe medication. Do we want them to one of those participating physicians? What level of attainment would be recommended by AMA?

Dr ZORBAS: I will start by saying that the AMA, both federally and in the Northern Territory, does not have a formal position on the necessary accreditation. I will say that the medical board has, broadly, three categories under which doctors are registered in Australia: general registration, specialist registration and limited registration. There are a few others, but for most functional purposes they are the three we are most concerned about.

We would not support limited registration. By limited registration we are talking about first-year intern doctors or doctors who are under a supervision plan, as international medical graduates coming to Australia or doctors who are registered in the public interest; for example, a US Army doctor who has practice restricted to a particular military base or something like that.

Across the jurisdictions there are variations. In general, the legislation supports those holding general registration for at least five years or specialist registration for at least one year, recognising that to have one year of specialist registration, they would have to have general registration, in almost all cases, longer than five years prior to that anyway.

We would support that from an operational point of view. There is no formal position and there could be alternatives we come to, but given that is the lay of the land across the jurisdictions, we would support that here as well.

Mr CHAIR: As a follow-up to that, is that position consistent with the 2024 report?

Dr ZORBAS: I would have to go back and check the report.

Mr CHAIR: My suspicion is that it may not be completely consistent, and I know it is one of the curly questions that we will have to wrestle with, noting that we do not have specialists in abundance in every area, let alone relative to every clinical diagnosis. If you can elaborate whether in writing afterwards, or now, that would be helpful for us to know.

As I said, again it comes to the question of capacity deficits. How many oncologists do we have, let along what subset of them would be interested in being involved in palliative care or separately a VAD service? Would that then allow us to be able to run a meaningful service? This is the sort of question we are wrestling with in that space, if you might be able to provide us with something.

Dr ZORBAS: Absolutely; I can take any question on notice around that.

To answer the question around accreditation and skills in medicine, VAD is a space that is not owned by one particular college; it is different from something like intensive care medicine, paediatric medicine or geriatric medicine where there is a dedicated college that is responsible for the accreditation and training of those doctors. VAD sits in a space that is shared across disciplines.

That is not unusual in medicine. We do this in retrieval medicine where most retrieval doctors involved in medical retrieval will come from a background of—sorry; to clarify, medical retrieval is the rescue and transfer of any patient, by helicopter or fixed wing, or the transfer between facilities or a pickup from a primary incident such as roadside trauma. That is a skillset that is not necessarily confined to one particular college. In practice that means across Australia you have emergency physicians, intensive care specialists, anaesthetists, rural generalists and sometimes general practitioners working in the retrieval space. Any doctor could be a retrievalist.

Doctors who choose a particular craft group tend to be drawn towards those types of fields. For example, most toxicologists have an emergency medicine background, but it is not to say you cannot be a toxicologist if you are not an emergency physician. Similarly with VAD, there will be doctors who have very specific interests in VAD such as general practitioners with a specific interest in VAD, or palliative care physicians. That is where we tend to see most of our VAD practitioners, in terms of their background. It is not to say that any other doctor could not become a VAD practitioner if that was an issue of particular interest to them and they had the requisite training.

Mr CHAIR: We are going at a rate of knots which is great, by the way; it is very helpful for all of us. I have lost my train of thought; it has completely escaped me.

Mr KERLE: One of the topics we have been chewing on is decision-making capacity. It is limited in the other jurisdictions. Does the AMA have a position on the assessment of decision-making capacity conducted in clinical practice and how might this process work in the context of VAD, given that every jurisdiction requires someone to be able to make fully informed consent to the procedure and understand fully the implications of it?

Dr ZORBAS: Above our VAD position is the definition of capacity which is paramount and is present in all medical decision-making above and beyond the issue of VAD. By that I mean that any patient that I might have in clinical practice—or any other practitioner—I need to know that they comprehend the information they have presented to them about their clinical situation and they understand what that means, they are able to retain that information, they are able to analyse that information and weigh up the risks and benefits of the options available to them and then be able to express and continue to express and hold that opinion about their care plan. That capacity has to be present for any VAD decision first and foremost. That is true of all medicine, that is not new for VAD.

While the AMA position statement is not prescriptive around operations of VAD—it is more high level than that and is more strategic rather than the operations of VAD—I will say that we do support the general common eligibility criteria for VAD across Australia which is that they should be at least 18 years old. Jurisdictions say that you need to be a resident of that jurisdiction; we support that for reasons of medical tourism and diversion of resources. We do not have a formal opinion on how long that timeframe needs to be. My understanding is that it is generally around 12 months, and in some jurisdictions it is two years.

There is the idea of connection to the NT that will be a bigger issue for us than other jurisdictions. There are people who may want to return to country, who have very strong spiritual connections to land and who have been living interstate for reasons. There should be a mechanism that we can assess that appropriately and make decisions around that and allow people that right of review rather than a very prescriptive rule.

We have people who live in the Territory for decades and then leave because they are seeking health services elsewhere because we cannot provide the service to them. It would be a perverse disincentive to them to then deny them VAD should that treatment no longer be an option for them and they want to return to die on their terms in their homes. Special attention needs to be paid on connection.

On the eligibility of diagnosis, again, the general criteria—which we would support—are that it is an advanced diagnosis, is progressive and will cause death. That is consistent with all other jurisdictions—also that there is an element of suffering that cannot be tolerated.

Earlier, my comments on suffering—it is very individual and is how it is interpreted by individuals. It is not my job as a doctor to tell people what their suffering is. They tell me what their suffering is, and I present them with the care options that I have available for them.

Most importantly, the decision to enter into VAD has to be voluntary. That is in step with every other jurisdiction. Noting the cultural concerns that I have expressed and language barriers as well, which also applies outside cultural barriers, we need to make sure that the service that we have set up allows people—we have confidence that people are entering into this on a voluntary basis.

None of this is new. That is all in step with the general principles of access to healthcare.

Mr CHAIR: On exceptions, the 2024 report suggested that there could be exceptions to residency requirements to recognise people who have connection to country or family or cultural links to the Northern Territory. Are those adequate to account for the situations that you are describing?

Dr ZORBAS: On the face of it, in my opinion, I say generally yes. We do not want something that is so prescriptive that it does not give people the right to make their case. A body like the NTCAT, as a right of appeal to what we decide is an appropriate residency situation or not, as long as the spirit of the language is around, having that connection to the NT and they have a legal right of appeal—I would have to defer to my legal colleagues on what that would look like—we would support that.

Mr CHAIR: That could be the VAD review board—it might not necessarily be NTCAT—who deems the residency requirement in this space. That is the spirit of where the report was at.

Dr ZORBAS: That would be fine, recognising that there would have to be a final legal point of appeal.

Mr CHAIR: Yes. Again, on the requirements for the review board, were the recommendations in the 2024 report broadly consistent with the thinking of the AMA, again noting precious commodity, scarce resources, limited doctors and limited time?

Dr ZORBAS: We are always limited. We always find a way. Central oversight is an essential part of the safe delivery of VAD, especially in a jurisdiction as large and as widespread as the NT. Recognising that the composition of the VAD review board would have to be legally empowered to oversee the process.

There needs to be a senior physician on that board, whatever that board and its composition might look like, with an effective ability to influence how VAD is operated in the NT. That would most likely be a palliative care physician. We also need representation from appropriate nursing, legal and pharmacy, but that is outside my representative body.

Aboriginal health experts would also be necessary—I would defer to bodies like AMSANT to provide you with more information about who would be best in that space to represent that view—and community representatives to make sure that the service is servicing the need of the community from their standpoint rather than ours.

Mr CHAIR: I recognise that you are not the peak body for nurses; however, nurse practitioners feature heavily in the literature, in discussions interstate and in the 2024 report. We have known limitations in that space as well. What role do you envision, with an NT lens on, for nurse practitioners or ENs or RNs for that matter?

Dr ZORBAS: It would be the same as our current multidisciplinary model of care with doctors and nurses in the way that we deliver healthcare at the moment. In something like that it would be physicians making the decision about eligibility and suitability and nurses being involved in, say, care navigation, delivery or administration of the medication—along those lines. We would not support nurse practitioners autonomously making decisions about entering into VAD. However, we recognise that there are significant roles for nurses and nurse practitioners in the delivery of VAD. A service would not be able to be delivered without their input.

Mr CHAIR: To be clear, your position is that those consultations and the execution of any treatment should reside in the hands of medical practitioners?

Dr ZORBAS: The consultations to decide eligibility and suitability should be in the hands of physicians, which is consistent with medical care delivery across Australia. When you say ‘execution’ do you mean the delivery of the medication?

Mr CHAIR: Yes, delivery of the medication for want of a better term.

Dr ZORBAS: Currently in medical practice, generally, nurses would be administering medication and substances on a daily basis, so it would fit with routine practice that it would be available to nurses and nurse practitioners.

Mr CHAIR: They would be part of team that might work onsite.

Dr ZORBAS: Correct. We do not support task substitution, but we support task delegation. Ultimately, you would have to be able to trace back to the VAD practitioners who made the decision about entering into that. They would be physicians.

K McNAMARA: One of the other curly questions we are working around is the idea about whether VAD, as an option, is allowed to be introduced by a practitioner in conversations with patients. Currently in Victoria it is not allowed to be, and that has caused a few issues. The 2024 report I think said that medical practitioners should be allowed to introduce the subject of VAD during discussions around treatment. Does the AMA have a position on that?

Dr ZORBAS: Zooming out from VAD and focusing on equity in healthcare, it is difficult to find other areas of medicine where we would restrict a practitioner’s ability to discuss healthcare options. The idea that VAD cannot be introduced into a discussion probably comes from earlier discussions of VAD when it was still contentious and was still unclear what the population of Australia supported as a concept. It is clear now that the majority of Australians support VAD, as is evidenced by the fact that we have legislative frameworks in all of the states and territories.

The AMA is not opposed to practitioners in the NT being able to introduce discussions about VAD. As is the same with all medical care, it is unacceptable for any form of coercion or direction from the physician that is not consistent with the patient's wants and needs. It is not the physician's job to drive that conversation, but it is our job to make sure that a patient has all the options that are available to them when it comes to end-of-life care. If there are legal prohibitions about the discussion of some element of that such as VAD, then I am not able to present them with the full spectrum of what their end-of-life care options are.

I will say, though, that the principle of conscientious objection still stands. There are areas of medicine where practitioners have elements of care that are not consistent with their firmly held moral or religious beliefs. We respect the right of all clinicians to not be forced to provide a service that they have moral objections to. However, in the setting of conscientious objection, it is the expectation of the AMA and the Medical Board of Australia—if you look at the code of conduct and the registration document we adhere to as part of our registration—that if you conscientiously object to the provision of medical care then you must provide a pathway for that patient to seek that care from another practitioner or service. That is standard in medical care in Australia. It should be the standard in VAD as well.

Mr KERLE: You got into the question I was about to ask about conscientious objection. For my benefit, could you summarise? On the one hand, we have not prohibiting practitioners from proposing it as one of the treatment options and on the other hand, we have the ability for practitioners to conscientiously object to participate and the ability for them to withdraw from that treatment pathway for a patient. What would that look like? If a practitioner were to conscientiously object when a patient asks them about an option, what is the expectation that they would facilitate or provide a pathway?

Dr ZORBAS: The expectation across Australia in a setting of conscientiously objecting is that an ultimate pathway is provided to the patient. That may be another practitioner who is in that current physical setting. For example, a discussion in the emergency department where there are many practitioners around, that may be a very simple and easy thing to do. It may be the provision of a telephone contact service so that they can be directed to a practitioner who can answer their questions.

That is currently done in areas such as medical abortion. There is conscientious objection to the provision of abortion services and not all practitioners provide abortion services. Those who conscientiously object in most states and territories are able to provide a central phone number or a central intake system which would direct you to practitioners who do provide those services and are experts in that area and trained in that area.

Mr CHAIR: In practicalities now, if we had a centralised standalone service the presumption would be, from you just said then, is that there would always be somebody on the end of the phone to be able to answer a question. We are not talking about as and when needs; a standalone service in your opinion would look like what?

Dr ZORBAS: From a resourcing point of view or from a …

Mr CHAIR: We are trading in hypotheticals anyway—right? The point is that we are hypothetically lurching towards a Bill that may then get hypothetically considered leading to a hypothetical implementation. It is useful to know what we are really talking about.

Do we need to build a new hospital which is the VAD hospital; or is it a series of practitioners who just come together once every six months to look at a series of cases; or is there someone permanently on the back of a hotline? The demand for this—this the sort of on-ground knowledge that you have that we obviously do not.

Dr ZORBAS: A hypothetical VAD service in the NT would be a Northern Territory-wide VAD service. If we look at the projection of numbers and our workforce demands here it would be very hard to justify multiple services around the Northern Territory.

There would be permanent staff. These would be staff who are dedicated to this VAD service. The reason for that is that there would be policies, procedures and governance around this that would need full-time staff to attend to. It is not something that could be done part-time.

It would not be co-located with palliative care services such as hospice at Royal Darwin or Alice Springs Hospital; it would be a separate facility, and it does not need to be onsite at a hospital necessarily. It could be at any suitable physical location.

There would be legal requirements around the storage of the medicines and substances we use. I will not speak to stuff that is already legislated in the Poisons Act.

There would be a combination of staff—medical, nursing, legal and pharmaceutical—and there would also be a remote delivery element to it as well. That may lean on existing services such as the patient assisted travel scheme where patients are brought to the service, or it may be that there is FIFO model where those practitioners head out to community, much like our outreach services for specialties in the hospital or our DMOs and general practice services.

Mr CHAIR: Could I impose upon you to take that as a question on notice and perhaps provide us something to that effect in writing. I just want to be clear the hypothetical model that you just posited—is that the Dr John Zorbas model or the AMA collective zeitgeist?

Dr ZORBAS: It is not a formal AMA position because we do not have a formal statement on operations. We have members, especially in the palliative care space, who have had experience with VAD, knowledge in the VAD space and are up to date with continuing professional development around VAD and would be best placed to provide a more detailed operational model that might work in the NT. I would be happy to take that question on notice and, from the AMA, go to our members and come back with something that is more tangible and operational for the NT.

Mr CHAIR: That would be fantastic and something context specific.

On the question of specialists, I am relying on our own consultation paper which drew out the fact that in South Australia and Victoria they require coordinating medical practitioners to have relevant expertise in the disease, illness or medical condition expected to cause the death of the person being assessed. The 2024 report proposed that this should not be a requirement in the NT because it could lead to barriers for access to VAD, noting there are major resourcing gaps in many health specialties across the NT. That is another question I would like you to chew on for us because we have concerns about what constitutes clinical judgement by a non-specialist in respect of terminal illness. This seems to be a critical question for us to chew on. If you will be willing to take that on notice.

Similarly, the original *Rights of the Terminally Ill Act* had a requirement for a psychiatrist to assess and confirm that a person requesting VAD was not suffering from a treatable clinical depression in respect of illness. The original proponents of that mechanism, by and large, concede that they think that is a superfluous requirement now. Can you confirm for us for the record what the AMA position on that might be?

Dr ZORBAS: There is no formal position. I can take the question on notice to take to our psychiatrist and palliative care physicians if you need something more detailed. What I will say is we tend towards the common delivery criteria across the country, which would remove that requirement.

Mr CHAIR: Thank you. Member for Wanguri, you are out of my line of sight, which is why …

Mrs CARLSON: I am okay.

K McNAMARA: I will ask a question about the reviews of legislation. Do you have any thoughts about the timing of how frequently—six months, two years, five years—reviews would need to be done on how it is running? What sort of things perhaps would need to be reviewed or looked at?

Dr ZORBAS: Please correct me if I am wrong, but in the consultation paper there is a general timeframe of about 18 months to stand up the service.

K McNAMARA: Yes, that is right.

Dr ZORBAS: That is doable. We can support that 18 months is a reasonable timeframe. To look at how that service is reviewed and how often it is reviewed, audit and active audit of any operational service would be a huge part of VAD. There are multiple answers to your question.

There would have to be case-by-case review of every case of VAD that we have, at least in the first year, and most probably ongoing, but I would leave that to future system design to decide on that.

There would to be a systems level review occurring at least quarterly to look at the system that is in place and decided upon and measure relevant KPIs about whether the service is effective. By that I mean that we need to be measuring tangible, patient-centred outcomes as to whether we are actually delivering the service we said we would deliver. It speaks to questions such as access in remote areas, ease of access, I suppose, in remote and rural NT, the use of interpreters, the uptake of VAD and whether it fits with the numbers we are seeing in other centres and, if not, why not—an active, three-monthly systems review.

There should be public annual reports on the function of the VAD service, total numbers seen and the cost of providing that service so that there is transparency on the delivery of service.

Legislative review is probably outside my scope to answer. I would leave it at that.

Mr CHAIR: Dr Zorbas, we are running short on time. This has been enormously helpful to start with. I will ask a final general question, albeit a pointed one. Wearing either your professional hat, as an individual or a representative of your organisation, what deficits are there in the 2024 report and/or model? What can you point us to that we could look at further with a view to refining or improving a model for the Northern Territory?

Dr ZORBAS: To answer that question properly, I have to say that I need to go back to the report again.

Mr CHAIR: That is fair enough.

Dr ZORBAS: I can speak to generalities. Maybe I can answer it by saying what has changed in the past 12 months. Telehealth would have to be the biggest one. Post-COVID the expectation of telehealth as part of medical care, even amongst the general population let alone doctors, is hugely important of our abilities to deliver care. The prohibition on using telehealth to provide access to healthcare in this setting—this unique problem we are faced with, VAD—ideally should be addressed. I appreciate that is a federal question and not necessarily something that we have complete control over, from a Territory point of view. It is something we would need to agitate for and address as part of any VAD service. The use of telehealth will significantly affect our outreach capacity and the resourcing requirements.

It is not necessarily the game changer in making the service viable or not from a financial standpoint, but it certainly means that we can do more with less.

Mr CHAIR: Equity of access?

Dr ZORBAS: Yes.

Mr CHAIR: Dr Zorbas, thank you very much for you time today. This has been enlightening. We appreciate you coming to speak before us, especially on short notice. We all appreciate that we are working to a tight timeframe. I do not image this will be the last time we will impose upon you.

We would like to see some of the answers to the questions on notice at your earliest convenience, noting that we are also working to a timeframe where we are seeking to report back to the Attorney-General by the end of September.

With that, I thank you very much on behalf of the committee for coming today. We look forward to progressing the agenda in tandem.

Dr ZORBAS: Thank you very much for having me.

The committee suspended.

Ms Judy Dent

Mr CHAIR: On behalf of the committee, I welcome everyone to this public hearing for the committee's inquiry into voluntary assisted dying. Today we will be talking about issues that may be distressing as they relate to death and dying. We acknowledge that these discussions can bring up difficult emotions. If people feel upset or need support, we encourage them to take a break. Support services are also available, the details of which are provided in the leaflets in the room as well as on our website. We thank everyone who is participating here for engaging in respectful and important conversations.

I welcome to the table to give evidence to the committee Ms Judy Dent. Thank you for coming before the committee. We appreciate you taking the time to speak to us. We look forward to hearing from you today.

As you can appreciate, this is a formal proceeding, so the protection of parliamentary privilege and the obligation not to mislead the committee apply. This is a public hearing and is being webcast through the

Assembly's website. A transcript is being made for use of the committee and may be put on the committee's website. If at any time during the hearing you are concerned that what you will say should not be made public, you can ask the committee to go into a closed session and we will take your evidence in private.

Could you please state your name and the capacity in which you are appearing.

Ms DENT: Judy Dent. I am appearing first as the widow of the first person to use voluntary assisted dying in Australia or, in fact, the world, and also as the President of the Northern Territory Voluntary Euthanasia Society.

Mr CHAIR: Thank you, Ms Dent. Would you like to make an opening statement?

Ms DENT: I would.

As you can well imagine, with the history that I have, I would like voluntary assisted dying legislation to be made as soon as possible. We have waited a long time to get back a right that we had originally in 1995.

Mr CHAIR: Ms Dent, tell us a bit about your story and your experience with VAD because not everybody will be familiar with your longstanding interest in the subject matter.

Ms DENT: Most of you were children at that stage, so you would not have paid much attention to it even it was in the paper.

My husband and I had virtually just arrived in the Territory. He had lived here previously. He was originally a lay missionary on Groote Eylandt, but then worked for the Department of Works and built houses all over the Territory. We were not supposed to be coming here to live. We were just coming to see how Darwin had regrown after Cyclone Tracy because Bob was a Cyclone Tracy survivor. I met him in Adelaide where he had been evacuated. His company, at that time, still had works up here, but their head office was Adelaide, so he just stayed with that company in Adelaide.

Fast-forward a few years, we decided that we would retire to Queensland. We were living in Victoria at that stage, but rather than going across to Queensland we thought we would go all the way around the outside, up to Darwin, see what had happened there and then move.

But when we got to Darwin, Bob was having a few problems. He went to the doctor and found that he did, in fact, have prostate cancer. The doctor here said he was not skilled enough to do a removal of the prostate and suggested that we go to Brisbane for that.

We went to Brisbane for that, but it turned out that the cancer had spread way beyond the prostate and removing the prostate would not help, so he had his testicles removed instead. It did not make much difference. The cancer progressed. It became more and more painful, more and more troublesome. I will not describe the symptoms and the problems he was having.

Then, out of the blue, Marshall Perron passed the *Rights of the Terminally Ill Act*. Bob said, 'I could use that', and he did. Unfortunately for the rest of the Territory, the federal government decided that we should not have such a law. How dare we? It has taken more than 25 years to get back the right for us to have that legislation again.

I am asking you to tell the rest of the government that a lot of people want this legislation again, as soon as possible.

K McNAMARA: Thank you very much, Judy. I think I can speak for all of us when I say that we really appreciate you coming in. As you say, it has been a long time and, I am sure, exhausting at times to see no traction effectively up until now.

I did not have any specific questions for you prepped because I just want to hear from you about your experience. Does anyone have any burning questions?

Mr KERLE: Hi, is it Ms or Mrs Dent?

Ms DENT: Ms now. There has been no Mr for a long time.

Mr KERLE: My dad passed away in 2008, so mum has been by herself since then.

Obviously this is a very sensitive topic. I thank you for coming today to share your story.

There are some people and groups who would prefer that this inquiry not recommend voluntary assisted dying to proceed. What would you say to those people, if there are people who prefer that the NT does not have VAD? I am trying to think how best to phrase this. What would your contribution to their argument be?

Ms DENT: Maybe I can help you. The key word is ‘voluntary’. If you do not want this legislation, pretend it is not here. You do not have to ‘obey’, you can do what suits you. Those of who want it would like to do what suits us, especially since it does not impinge on people who do not want it; they can just pretend it is not there. If it is not there, it puts the rest of us who want it in a bit of a bind.

Mrs CARLSON: Referring back to the comment you made in your opening statement about your late husband, Bob, who was a lay missionary. I am curious to understand or get your insight. There are some groups who do not want voluntary assisted dying due to probably their cultural or religious beliefs—or any belief really.

I am interested to find out if you can allude to how Bob came to decide when it became legislation to use. Did he have any previous beliefs and were they changed? Was there any reason?

Ms DENT: We did not actually discuss whether he had ever thought of it before. I know that when the legislation was proposed and it was in the paper and all the rest of it, he was interested. Because he was not in a life-threatening situation before it probably never occurred to him. When it occurred to him he thought, ‘That sounds like a good idea’, and he followed it through, which was not simple.

Mrs CARLSON: Obviously conversations before probably were not simple; they would have been hard. It is a hard decision to make. Was there anything that you believe or could give insight to about how conversations can be held in a more respectful way for the community?

Ms DENT: No, I …

Mrs CARLSON: Did you have any other support during that time? Was any support available?

Ms DENT: No. He joined the group that was supporting Marshall Perron in his quest to have the legislation, but I was too busy working, making the money to feed us both and looking after him and all the rest of the things I had to do. I never went to a meeting. I am not sure he actually went to a meeting; I think he just phoned various people and talked to them. He did not say, and I did not ask.

Even if I did not believe in voluntary assisted dying, I was not the one with the problem; I was not the one suffering. I was suffering in a different way, but voluntary assisted dying would not help there. We really did not discuss it much because I knew once he had made up his mind that was it; I would not change his mind, even if I had wanted to. I did not because it was his body. He was the one suffering. Even if it is not purely physical suffering, mental suffering is worse sometimes. I did not argue with him. We hardly discussed it at all, except to think, ‘Now we need a second signature from another doctor. Who will we get?’

It was always we; it was not one against the other or anything like that. Very fortunately, nearly all the suggestions I made were good ones and we managed to get all the signatures. But even at that stage we were waiting in the waiting room to speak to a doctor. Everybody knows who it is now, but nobody did at the time, and it was one of those mixed surgeries with a different doctor in each room and a huge waiting area.

Philip Nitschke came in because under the Act he had to witness the signature of the second doctor. Bob and I were going to go in and speak to Mr Wardill and if he agreed, we would get Philip in to witness the signature before anybody changed their mind. While we were waiting, several people walked up to Philip and shook his hand and said, ‘Keep it up. We need this legislation. We don’t want to lose this legislation; you make it work properly.’ Even though we were not discussing it, obviously a lot of other people were.

Mr CHAIR: Ms Dent, I am going to impose upon you in your capacity as the Voluntary Euthanasia Society representative here to give us a bit of an understanding about how large that group is and how active you are in this space. Can you give us a few details initially about that?

Ms DENT: Unfortunately, the group is a lot smaller than it used to be because when it was formed, everybody was trying to get Marshall’s legislation through, so there were—I think our mailing list was about 140 at that stage. Of course, once the legislation was passed everybody said, ‘That is done’, and they all left the Territory virtually—well, quite a few of them left the Territory. Because the initial passage of legislation was followed by the federal legislation, everybody said, 'Pfft', and just disappeared. What can we do about the feds? We cannot do anything, so we are lucky to have maintained a membership of between 25 and 30, and of course we are all getting a little bit older now and we keep dying, and very few young people even think about it, so they do not join.

Mr CHAIR: In recent years you would be aware, of course, that there have been lots of moves on voluntary assisted dying across the country, and most recently in the Northern Territory an independent inquiry in 2024. That inquiry is in fact the focus of our inquiry. We have been tasked with looking at the final report, its recommendations and the model that they suggest for moving forward. We are trying to do a final round of supplementary consultation, not to supplant what has been done in the last 30 years, but to supplement it.

Do you have an opinion about the 2024 independent report or any of the details contained within?

Ms DENT: I think the report is a bit on the timid side primarily because they wanted it to be acted upon. That is just my opinion, but I think that is what is going on. They did not want to scare the horses.

I would like a much gentler legislation without quite so many restrictions, but that is not going to happen, so I am quite happy with most of what they have requested.

Mr KERLE: When you say 'without so many restrictions', can you list some of those restrictions in order to have gentler legislation?

Mrs CARLSON: What would your recommendations be to meet the eligibility criteria then?

Ms DENT: Sorry; I should have written this down.

Mrs CARLSON: That is okay; take it easy.

Mr KERLE: Take your time.

Ms DENT: It should not be so difficult to get the required signatures. It should not—sorry.

Mr KERLE: You are okay; thank you.

K McNAMARA: In your advocacy over the many years, even though the society might be small now, you would have spoken and heard people's stories over the years—people who had wished perhaps that we had the legislation after it was taken away. Do you have any stories or thoughts to share of what you have seen in the Territory over the years, after we had the legislation and then it was repealed, of how that has been particularly for people that you might know who have had terminal illnesses?

Ms DENT: I cannot give you any examples because the people generally I knew who were given a bad diagnosis had relatives in the rest of the country, so they moved. Hardly anybody that I am aware of stayed here. For the people who have relatives elsewhere and they can move in with them, that is fine. But I hope they realise that there is a one-year residency requirement.

That is something that we need to make sure does not go into our legislation. There should be no residency requirement because someone might come up here so that they can die where their children are. They should not have to move up a year or two ahead of time or whatever. The state legislation is the most. It is a year. I will not swear to that now. I have read them all, but I cannot remember them all.

K McNAMARA: This very topic is in the report as well as in this consultation paper. It is mentioned in terms of people having cultural or family connections, and we have also heard from previous witnesses about making sure that there is flexibility in that for people from interstate who have connections here.

Mr KERLE: This might speak the question we had before. When Bob went through the process those years ago—I appreciate that it is nearly 30 years ago now, and it might be getting hard to remember all the details—you mentioned a few signatures that you had to get. Could you walk us through the process of what you had to get done in order to go through it? Were there things in that process that could have been done better from the government's side?

Ms DENT: It was brand new. Most people just had a 'not sure I want to touch this' sort of feeling. Philip Nitschke unfortunately upset the Territory government by saying that the American nuclear submarine was allowed to visit Darwin Harbour and we did not have a plan if something happened. That stirred up an awful lot of problems for Philip who then did not get his contract renewed. It is my supposition that it was because of the nuclear submarine business.

By this time, Bob was under the care of the palliative care people. The doctor there said, ‘You realise I have 40 patients. If you need help after hours, you will not be able to phone me. I do not have spare hours.’ So, we phoned a 1800 number which turned out to be Philip Nitschke. I had not known Philip even though I worked in the hospital. I had not met or spoken to him. He became our after-hours doctor. When the legislation was passed, Philip immediately began devising a way for the patient to control the whole thing. Bob had asked him on occasions—he came to our house at 10 o’clock at night several times; I cannot tell you how many times, many times—and they had discussed this. Philip said he was working on a way to put the control back in the hands of the patient.

I do not know where I was going with this story.

Mr KERLE: You said you had to get signatures.

Ms DENT: Okay. The first thing you had to do was get a doctor to say, ‘Fine’. Philip was the first signature. Then we needed someone with sufficient experience to be the second person. I will not name names, but most people said no.

I took it upon myself to write a letter privately to Jonathon Wardill and then later suggested to Bob that perhaps Mr Wardill might sign. We discussed it with Philip and Philip said, ‘I do not know’. I said, ‘Well, I have made an appointment. We will see him and ask him.’ We made the appointment; we went to see him. Bob had seen him previously and, in the meantime, he had lost about 40 kilos. When we walked in he said, ‘Oh my god, Bob, what has happened?’ We explained the new legislation and that we needed the second signature. He said, ‘All right, I will do it’. I immediately ran to the door and called Philip in because he had to witness the signature. He signed it and handed the paper back to me. The look on his face was, ‘Oh my god, what have I done?’, but I did not let him have the paper back. I kept that piece of paper.

Then we had to have a psychiatrist. A local psychiatrist was not interested at all. Philip rang every psychiatrist he knew in the whole country and one said, ‘I am interested. I could sign it, but I think it would have more clout if you could get Professor Ellard to come up.’ Philip phoned Professor Ellard and he said, ‘I most certainly will do that. Book me a flight; I will come up whenever you can book me a flight’, and up he came.

This is totally coincidental. By this stage Bob had become a Buddhist and Professor Ellard turned out to be a Buddhist.

Anyway, Philip and I were sent away while Bob and Professor Ellard had their discussion. He signed the piece of paper and then everything was set; we had all the necessary bits and pieces taken care of. Then one Friday Bob said to me, ‘Ring Philip and invite him for lunch on Sunday and tell him to bring the gear’. Philip came and he set everything up. He had to put the needle in the arm, but the fluid was not flowing until Bob answered the three questions on the computer, which concluded with, ‘Are you sure this is what you want to do?’ ‘Yes.’ The fluid started running into Bob’s arm and immediately the pain lines on his face just went. He looked so peaceful.

Philip had set it all up on our veranda because in the Dry Season Bob found it too cold in the house. We do not have air conditioning. We never have had air conditioning, but it was just too cold in the Dry Season, and he used to have a bed on the veranda with shade cloth to minimise the sun, so he did not get sunburn but enough to get the warmth from the sun.

Anyway, I stood with him, and I promised him I would not cry until I knew he was definitely not waking up this time, and then I cried because he could not see me to see I was crying. Philip came and signed the piece of paper, the little death certificate, tidied everything up and put all his gear back in his car and drove away.

About half an hour later I phoned the funeral parlour and I said, ‘You can come and collect him’. Bob had already told me which funeral parlour we would be using and what he wanted and what he did not want. We had just what he wanted.

The Buddhists have a special ceremony 50 days after death and 100 days after death. For his 100th day I hired a float plane and sprinkled Bob’s ashes in Darwin Harbour. Not many people know Bob had a private pilot’s licence and his favourite plane to fly was a float plane, but when we got to Darwin nobody was renting out planes to individuals, so he could not do that anymore. Every time I had a shift that included a Saturday morning when we still lived in Adelaide, he would go and fly a plane while I went to work, so I thought it was very appropriate that his ashes be scattered in Darwin Harbour because that is where his heart was. Even when we lived down south, he really wanted to be back in Darwin. He considered it a lucky thing that he found out he had cancer before I made him move from Darwin to Queensland.

Mr CHAIR: Ms Dent, thank you for sharing your story with us today. We are limited in time and so must move onto the next witness. We thank you very much for coming to share your story and your insight today. It is important for us to connect with people who have lived experience of VAD and are connected to it in more than just a technical way. Certainly, it has been enlightening for all of us to be reminded of Bob's story today, so thank you for taking the time.

Ms DENT: You are welcome. Any questions, email me. That is as far as my technical knowledge goes.

Mr CHAIR: For most of us, it is the same. Thank you very much, Ms Dent.

Mr Wayne Wood

Mr CHAIR: Mr Wood, thank you very much for joining us today.

Mr WOOD: Wayne, please.

Mr CHAIR: Wayne it is.

On behalf of the committee, I welcome everyone to this public hearing into the committee's inquiry on voluntary assisted dying. We are discussing issues today that may be distressing to people as they relate to death and dying. We acknowledge that these discussions can bring up difficult emotions for some people, so we always say to everyone that if you feel upset or need support, we encourage you to take a break. Support services are also available, the details of which are listed on our website and on the pieces of paper floating around the room. We thank you, first of all, for your participation today. We encourage everyone who is participating in these discussions to do so respectfully.

I welcome to the table to give evidence to the committee Mr Wayne Wood, henceforth Wayne. Thank you for coming before the committee. We appreciate you taking the time and look forward to hearing from you.

This is a formal proceeding of the committee and the protection of parliamentary privilege and the obligation not to mislead the committee apply. This is a public hearing and is being webcast through the Assembly's website. A transcript will be made for the use of the committee and may be put on the committee's website. If at any time during the hearing you are concerned that what you will say should not be made public, please specify so and the committee may go into a closed session and take your evidence in private.

Could you please for the record state your name and the capacity in which you are appearing.

Mr WOOD: Wayne Wood. I am a private citizen. I have a unique experience of assisted dying or experience more of the mechanics of what goes into it, but nothing like the experience of Judy.

I am a little hard of hearing, so could you speak up? That way I will understand you better. I will not have to lip-read.

Mr CHAIR: Absolutely.

Let us start by hearing about your experience by way of an opening statement.

Mr WOOD: When I started off, I said that my understanding is, and I wrote where we are up to, but I do that with an enormous sense of deja vu because I was sitting in this building 30 years ago doing the same stuff at the original submissions for the legislation.

The first thing I want to say is you should not have changed the name. Voluntary assisted dying fits in nicely with all the other states, but we were first and we put a nomenclature on it that suited it perfectly. It is all about the rights of Territorians.

We have gone from first where everybody understood. There were some—I was a very good friend of Chris Wake. We took totally opposing points of view over the rights of the terminally ill; his was religious based and mine was based on experience. As a result, we fell out pretty badly. The last I heard, he was conducting some sort of medical practice in a Tasmanian jail. I do not know where he has gone from there. It was not easy. Listening to Judy, she had it even harder because she had to deal with people like Philip Nitschke. When all this was happening, most of you were still in school. You did not understand the fractions that occurred in society over this business.

I just came in on the end. My son had just died, and I felt that it was important that people on the committee then knew the emotional environment that you had to live through. I came along just to add some colour. I did not know any of the legal things involved. I did not understand anything like the machinations that you had to go through, the technical detail that you had to go through, but I wanted to get a couple of ideas across to the committee.

The most important one to me at the time was the fact that the legislation relied far too much on the medical profession. My criticism of the stuff that has been done since and the 2024 report has not changed. I listened to the guy before and it has not changed again. You are still relying upon a bunch of people who do not have anything like the experience of Judy Dent. You are relying upon a bunch of people who probably would not experience this sort of thing more than once or twice in their lifetime. For the doctors to say, 'Oh, I think you should be doing this', no, no; you are the legislators. You come up with an Act that is for the benefit of the majority of Territorians, not an Act that complies with what the AMA wants. That is my biggest criticism.

I will go through a couple of other things. I want to update that within the 30 years since my son died, my mum and dad have died. My dad was 88. I was talking to Matthew about it. Both my mum and dad were teachers. They had good, long careers and eventually, as they got older, they went into a nursing home. They were in a nursing home where they had the hospital alongside.

When my dad became frail, he went into the low-care nursing home and it was awful. It only took him about three years to get to the stage where he became a vegetable, surrounded by vegetables everywhere. Seriously, if any of you go to one of these places—I do not know whether Pearl is like it or whether they have anything up here. Certainly, in the states where they have large populations of older people, there are all these people taking forever to die and it is awful from a child's point of view. It is fairly difficult to look at me and say, 'There is a child', but believe it or not, I did have mum and dad.

Mum lived in a little flat alongside the hospital; dad lived in the hospital. It took him a long time to die. Every winter he would get an upper urinary tract infection. They catharised him; they put him into ICU. He screamed and cried the whole time. He did not understand what was going on. His understanding of life was limited to Saturday afternoon, because he was a lifelong AFL fan, and he would sit and scream at the umpires because he was an umpire. That was his life. He did not understand when he got sick, and they put him into ICU. They would stick a catheter up his dick and put bloody medicine down and he hated it. He drifted along and drifted along.

I went to a 30-year work reunion. I went down there one time, and he was sick while I was down there. I went straight around to the medical people in this hospital part, and they said, 'All we normally do is fill him full of painkillers and send him off to ICU'. I said, 'Don't. Just fill him full of painkillers. Let him go'.

I had three brothers, and I got them all in and we went as a group along to the doctors and said, 'We want him to die; he wants to die'. That is all they did; they filled him full of painkillers and let him die. It was good.

Five years later, my mum, who was 93 at the time, fell over in my brother's shower. She was embarrassed by that because her son had to come and pick her up and she was naked. She had been leading up to it, 'I am 93'. She was not particularly ill. She was one of 13; she was the second youngest of 13 siblings. I did not know until afterwards that during the decade before she died, when one of her siblings got ill she would contact them—they all lived in New South Wales—and say, 'Do you have any painkillers left over?' They usually said, 'Oh, yes, I have some heavy shit', because these were all old, old people.

She got the painkillers sent to her and when she decided to go—this was before South Australia had legislation—one night we got drunk drinking white wine; she went to bed, took the painkillers and it was a brilliant way to die.

I rang up and the police came round, because she did this without my knowledge. I was not participating in it at all. We rang up the GP and she had instructed the GP to tell the police that she had a heart attack. When the police rang up and said this lady has died, 'What is the story?', the quack said, 'She's had a heart attack'. They said, 'All good; fine', and everything, and it was so smooth and organised. We got all emotional and had a little cry, but the differences between dad who was screaming in pain and we did not know quite what to do, and mum who had organised it herself—brave woman that she was—who would just sort of fit in with the system.

That is what I want for Territorians. We need to have a system which is almost divorced from medicine as we know it.

People choose, because it is a choice, and that is what Judy was very important about. That is what I am trying to make a point of here: that it is all very nice for you educated people sitting there, making rules and legislation and the rest of it, but as I have said in my paper you take that out to the majority of people in the community, particularly in rural and remote communities, they have not got a clue what you are talking about. The V in voluntary assisted dying must be the highest priority.

As Judy said, if you do want anything to do with it you do not have to have anything to do with it; just step away. Let those people who want to be assisted in dying—give them an unobstructed pathway. They should not have to go through the rubbish that Judy went through. Dealing with people like Phil—has anybody ever met Phil? If you really want to know …

Mr CHAIR: Just on that note, I will be cautioning you. To speak adversely of another person in a committee hearing, often we go into session. If you have anything specifically critical to say about Mr Nitschke …

Mr WOOD: No, I will not. If I do say anything that offends anybody, pull me up; tell me and I will stop.

Mr CHAIR: I am just cautioning you in the interests of procedure.

Mr WOOD: Phil Nitschke was a unique personality. If you really want to know what he did, read a book called *The Peaceful Pill Handbook*. That is the only book I know that has been banned in Australia because it actually has specific instructions on what medicine to use, what dose you should use and how you insert the needle and the whole lot. If you want some background on what Phil Nitschke did, read *The Peaceful Pill*. I am not sure that you can even get it because I know it was banned for a long time. It went through all the processes. I will slow down.

The points I was trying to make is that:

(a) We have been through this process. I have been through this. Judy has been through this, and you will probably find that other people you are speaking with have been through this process for 30 years. I know you want the background and have to be brought up to date, but please in September when you write your report, the most important thing up-front is do it—get it done.

(b) Do not listen to doctors. Yes, they are the ones that probably have to do the injection in the end, but, generally speaking, you will find a lot of the brave people who have made the decision and want to go ahead, they will find some way of doing it themselves anyway.

I think it is important that you understand the report done in 2024 had the numbers. They did all the surveys, and they showed that in excess of 70% of people are in favour of it. It is no coincidence that 30% of the population are Aboriginal. As I said in my paper, you will find there are a lot of people in rural and remote communities who have no idea. They are white cockys—they fly in, shit all over the place and fly out. They make a lot of noise, but have no idea of what is going on. That is very important.

The questions for consideration in 2024, I think were all suitably addressed. I do not think you need to make many additions or changes, with the exception of stressing ‘voluntary’.

Mr CHAIR: Mr Wood, I …

Mr WOOD: I have just about finished, so …

Mr CHAIR: That is all right. I was going to say thank you very much; that was comprehensive and informative. I read your 1995 submission. It was informative then and it remains pertinent now. Everyone on the committee is aware that this is an issue that has not been resolved for the best part of 30 years. We are doing the best we can to move the issue forward as quickly as we can, noting that the world has also moved on in some regards.

However, we take two points seriously. One is the V in voluntary being paramount and two is the nomenclature rights of the terminally ill is held dearly to many Territorians. Those are two things we shall certainly reflect upon.

I will pass this on to my committee members now for any questions they might have. Matt, did you have anything specific you wanted to ask?

Mr KERLE: Wayne has already covered it pretty well.

K McNAMARA: Because you were there at the start and are here now, apart from the things you have mentioned, is there any change along the way or things—perhaps issues you did not see initially that you have learned that over the years, seeing us had this taken away from us and now potentially brought back again?

Mr WOOD: Yes, I have lived here 45 years. I came up on a two-year contract and did not go home; did not go back to Adelaide. I am proud of being a Territorian; I like it. When all this was happening, I thought to myself, 'Hey, we are a good bunch of people. We are way out in front here; nobody else has done this. We are almost as good as the Dutch'—because they were way ahead of us.

I always have a soft spot for Phil Nitschke. He worked hard. The big changes Judy has said is we have gone from a situation where, as proud Territorians we would say, 'We are grasping the nettle and introducing this legislation'. It was controversial at the time. I was telling Matthew my understanding of the situation was it was evenly balanced. There was just one guy out at Arnhem Land whose mother had died pretty badly and he came in on the back of that and said, 'Yes, yes, we need this legislation'.

The things that have changed are that I have noticed that there does not seem to be the passion for it anymore. I think if we got a group of ordinary Territorians and sat them down at a pub somewhere and said, 'Guys, let us get enthusiastic about this; it is important as Territorians', most of them would say, as Judy alluded to, 'Yes, mate, if I get prostate cancer I will just live in South Australia for a year'.

I pointed out in quite a nasty, cheeky note to you that the old, rich people up here could have a significant effect on the economy if they all decided to go and live in South Australia, Victoria or New South Wales when they get prostate cancer. You would be doing a good thing for the economy if rich old men or rich old people who got cancer here stayed here and spent the money here.

The main thing I have noted in response to your question is we are not passionate about it anymore, as we used to be. You could do a good job for both as representatives and for the Territory by saying, 'We want to be number one again. We want to have the best legislation in Australia. We want to make it the easiest situation for Territorians who get ill and choose to die.' That is what it is really all about. We have to get this atmosphere, this environment—if you are against it, step aside. We are not making it compulsory. We will not turn around and say, 'You have prostate cancer, and you will die in 12 months. You must do these things.' If you do not want to do it, step aside. Let it go. Come up with legislation that recognises that. Start with a big V that says it is all voluntary. No-one will force you to do anything. You get to choose.

I am referring to rights. As a Territorian, I am disgusted that Andrews introduced legislation that took away my rights. I hope he rots in hell. That should never have been done. We should never have been placed in the situation where you people have had to do a whole lot more work.

Mrs CARLSON: Because this has taken so long to come back into the conversation and being at the forefront again, do you think part of that has been from life expectancies being extended now due to modern medication and the facilities that we have now in trying to prolong people's lives with some of the illnesses that would be relevant to this legislation? From a personal perspective rather than a medical, technical person's perspective, do we as a committee need to look at the definition of suffering on a personal level in how we consider having it written in the legislation so that it can be part of the conversation with our medical practitioners when we need to make choices?

Mr WOOD: Two things—first of all, before you have the conversation with the medicos, separate out those who are for and against.

Before our son died, we went to the guy who was prescribing the morphine and said to him, 'What if we all agreed in extremis, right towards the end'—I will not describe towards the end, but it was horrible—'what if we said we need enough morphine to send him on his way?' He said, 'No way. My medical licence would be suspended.' So, we reached a compromise where he would give us a week's worth of morphine at a time.

Had we administered that in the way that we knew what the end would be, we could have done that, but for a variety of reasons we did not do that.

One of the reasons was because I was frightened of the nurses who came around and changed the dressings. I thought if anything, they would be right there and jump all over me. We did not do that, but that should not be an inhibitor. You should not have to.

The previous speaker, the guy from the AMA, made the mention that right up front, one of the first things you do is put it to your GP or the person who signs off and say, ‘What is your attitude towards voluntary assisted dying?’ I have done this with my GP. Both my wife and I have an advance care plan. We have stipulated at the end in bright, big, bold letters, ‘I want the right to die’. There should not be any argument. It is there in writing and registered with whoever.

Your point—I am sorry; I have got off the subject.

Mrs CARLSON: I have question on the back of what you just said there. You have your wishes stipulated in the advance personal care plans. If we are to give drafting instructions, is that something we should make sure is still a consideration in line—side by side?

Mr WOOD: Yes, make sure everybody over 70 goes to a COTA seminar when the people from one of the government departments will turn around and say, ‘This is what you do. There is a template up online, go and fill it all in. Put in there “In the event that I have incurable cancer, I want to take advantage of the right-to-die legislation.”’ There it is for the doctor. If the doctor says no, then the guy from the AMA says he has a conscientious objection, right at the very beginning you move from that guy who is objecting and has every right to do so—it is the same thing with abortion and a whole bunch of other stuff—to someone who is like Phil Nitschke or one of his crew who say, ‘Yes, I will do all the paperwork for you; run around and get all the signatures for you and fill in the form for you.’ Because if you are dying or taking care of someone who is dying, you do not have time for that rubbish. They come along and put all the forms in front of you to sign, and it is done and dusted. Getting an advance care plan—or whatever it is—is absolutely crucial. Everybody over 70 should have one.

Mr CHAIR: On that note, I am going to have to cut you off because we need to move on for time. You are obviously extremely passionate about the rights of the terminally ill and voluntary assisted dying. We all know that from the number of emails we have all received from you over a long period of time. It has been very enlightening to hear what you have to say in person, in addition to the witness submissions you have provided us previously as well. We encourage you to resubmit any of what you have provided us as a formal submission if you would like to do so, and we will add that to the body of evidence of everything we are looking at.

As I say, the V in voluntary, the nomenclature, simplicity of process are all things we will be thinking about off the back of your contribution today.

With that, we are going to have to move on because we have another set of people to address.

Mr WOOD: Now I recognise some of the faces.

Mr CHAIR: There you go. Thank you very much for taking the time to come down today.

Mr WOOD: My pleasure. Thanks very much for the opportunity to speak.

Mr CHAIR: We look forward to maintaining the dialogue with you.

Mr WOOD: You will hear from me.

Mr CHAIR: I have no doubt.

Mr WOOD: Appreciate it.

Mr CHAIR: Thank you.

The committee suspended.

NT Health

Mr CHAIR: On behalf of the committee, I welcome everyone to this public hearing for the committee's inquiry into voluntary assisted dying. Today we will be talking about issues that may be distressing as they relate to death and dying. We acknowledge that these discussions may bring up difficult emotions. Consequently, if anyone feels upset or requires support at any time, we encourage you to take a break. Support services are also available, both on our website and articulated on the pieces of paper on the desks. We thank everyone participating today for engaging respectfully in these important conversations.

I welcome to the table to give evidence to the committee Mr Chris Hosking, Chief Executive of NT Health; Dr Paul Burgess, Acting Chief Health Officer; Dr Jeremy Chin, Chief Medical Officer; and Dr Kane Vellar, clinical subject matter expert. Thank you very much to the four of you for availing yourselves today. We appreciate you taking the time to speak to us and look forward to hearing from you.

This is a formal proceeding, as you are aware, and the protection of parliamentary privilege and the obligation not to mislead the committee apply. This is a public hearing that is being webcast through the Assembly's website. A transcript of the proceedings will be made for the committee's use and may be put on the committee's website. If at any time during the hearing you are concerned that you will say something that should not be made public, you may ask that the committee goes into a closed session and take your evidence in private.

Could you please each state your name and the capacity in which you are appearing, beginning with you, Mr Hosking.

Mr HOSKING: Chris Hosking, Chief Executive, Northern Territory Health.

Dr BURGESS: Dr Paul Burgess, Acting Chief Health Officer, NT Health.

Dr CHIN: Dr Jeremy Chin, Chief Medical Officer, NT Health.

Dr VELLAR: Dr Kane Vellar, Consultant Psychiatrist, Palliative Care Consultant with NT Health and former member of the expert panel on voluntary assisted dying.

Mr CHAIR: Mr Hosking, would you like to make an opening statement?

Mr HOSKING: Yes, a brief one, Mr Chair.

Good afternoon, Chair and members of the committee. I am Chris Hosking, chief executive with the Northern Territory Health department. Thank you for the opportunity to appear before you today and provide expert advice and answer questions about voluntary assisted dying from NT Health's perspective.

Before I start, I acknowledge we meet today on the land of the Larrakia people, traditional custodians and storytellers of these lands and waters for many thousands of years. I pay my respects to the Larrakia elders, past, present and emerging and I acknowledge any First Nations people who join us here today.

I am here today with my colleagues. To give you some background on the depth of the participation, you have in front of you: Dr Paul Burgess, the Acting Chief Health Officer, who has practiced medicine in the Northern Territory for decades, including in many remote bush settings; Dr Jeremy Chin is our Chief Medical Officer and remains a practising clinician; and Dr Kane Vellar who, by way of his introduction, is a clinical subject matter expert in this particular matter.

Voluntary assisted dying is an important subject and a complex issue. The Northern Territory faces a significant decision regarding whether to introduce legislation to enable voluntary assisted dying, a matter in which there is a diversity of views and values across our community. Voluntary assisted dying is an end-of-life option that enables eligible individuals who are dying to choose the timing and circumstances of their death. It is intended to offer an option to limit suffering during terminal illness.

As you would be well aware, currently other Australian states and territories have legalised VAD, making the Northern Territory the only jurisdiction where this is no longer legal. There has been extensive consultation on VAD involving the community, stakeholder groups, medical and legal experts as well as various organisations. This process has identified substantial public interest in the issue and also indicates that a significant portion of Territorians support the introduction of VAD legislation. Many recognise VAD as a personal choice and believe that individual opposition should not restrict access for those who wish to pursue that option, providing that comprehensive safeguards are established.

NT Health has previously had a VAD legislation and implementation committee, with membership comprising experts across clinical medicine, nursing, allied health, Aboriginal health, legislation, policy and public health. Should legislation be enacted here in the Northern Territory, NT Health is well positioned to assist and provide advice regarding models of care and modes of service delivery. We are also able to provide appropriately qualified, trained and experienced staff to undertake work required to consider the culturally safe and effective implementation of VAD should it be required.

We are incredibly respectful of the complexity and sensitivity of this issue, and I am very capably supported by my colleagues today who can provide subject matter expertise to assist the committee in this matter. We appreciate the opportunity to appear before you today and we look forward to questions from the committee.

Mr CHAIR: Thank you, Mr Hosking, and we appreciate that you have come together, all four of you, on short notice for us today. It is that subject matter expertise of your colleagues that we want to lean on in particular today.

As you will be aware, this committee has been charged with undertaking an inquiry on specific terms of reference, the focus of which is the 2024 expert panel report and the recommendations contained therein. We are looking to interrogate to some extent, whether the model proposed under that report can be attenuated, improved, whether there is new information that we can bring to bear that might help us come towards a workable model in the future and a Bill along the way as well.

That being the case we are going to ask some similar questions to the ones we put to the AMA earlier today, seeking to interrogate what VAD might look like in the Northern Territory and what specific limitations or critiques you might have of the 2024 report.

I will begin by asking you about the requirement in the 2024 report that there not necessarily be a requirement for a relevant person with expertise and experience in a disease, illness or medical condition to be part of an assessment process in the final stages of things. In 2024 it was proposed that requirement could lead to a barrier to VAD in this jurisdiction, noting that there were major resourcing gaps in health specialties in the NT. Palliative care comes up a lot and in the discussions we have had today. I am curious if you can speak to what we might do to deal with the problem of clinical judgement by non-specialists in respect of VAD in the Northern Territory—to all or any of the subject matter experts.

Dr BURGESS: Perhaps I can start. The assessment process for VAD that was outlined in the report was a three-stage process. The first stage was really the entry into that, and that could quite typically be a general practitioner who a patient is consulting for the first time. As a GP I can speak to having decades of experience in managing patients with complicated illness. That is appropriate for the first entry point into the VAD process.

There is the second stage of the second opinion, which is often a specialist with subject matter—if it is a cancer it would be an oncologist, or if it is motor neuron disease, for example, it could be a neurologist who can provide, importantly, information about prognostics in terms of the length of time until the likely end of life. That is critical for the intended 12-month frame for the expected application of the VAD process.

The third stage is, after a cooling-off period, for the patient to make a signed statement of their intention and have that witnessed. That initiates the process where the medication can be supplied and decisions made about self-administration or administration by a third party.

The requirement for a specialist is only for one of those steps, and it is an important validation step to make sure that those initial assessments made by, normally, a GP would be accurate and reflective of the patient journey.

Mr CHAIR: In practical terms, that second step, the clarification by an expert—how would we manage that situation if the capacity deficit exists in our health system to have somebody with the appropriate sub-specialty necessarily to make a clinical judgement?

Dr BURGESS: It is a good question. One of the major issues around the country that we are encountering with the VAD legislation is at the moment we are still unable to use telemedicine for us to do consultation. There has been a private member's Bill—Kate Chaney's Bill from WA—that has not made it through the past federal parliament. I understand it will try to be again prosecuted in the new parliament to make it possible for a carriage service to be used—telemedicine, for example.

If that barrier was removed that would, obviously, increase markedly the access to specialists. It may be that a specialist in a specific illness may not even need to be resident in the Northern Territory, for example, and telemedicine can access that expertise around the country if needed.

It is important that at least one of those consultations, as written in the report, should be face to face to assess that there has been no evidence of coercion in the decision for the patient.

Mr CHAIR: In the event that the limitation does not move forward, can you see a workable way forward for us to run a VAD service in the Northern Territory?

Dr BURGESS: That is a good question. We are good at workarounds in the Northern Territory. The challenge will be that some patients are too unwell to travel. That could be a limitation at earlier stages of the illness in the 12-month period of the expected illness. Patients may well be able to travel, and that might be an option. We can use the existing patient travel services to get them to a face-to-face specialist appointment.

K McNAMARA: Following on from that, with the telehealth restrictions we have with the Commonwealth legislation, currently is telehealth a large part of the healthcare system in the Territory?

Dr BURGESS: It depends who you ask. There is certainly some craft groups have been strongly adopting telehealth. GPs who only spend short amount of times in remote communities often use telehealth. A lot of specialty colleagues, particularly in psychiatry, have been our strongest proponents of telehealth. There are some medical specialties for which they need to put their hands on the patient, and telehealth is not as appropriate.

In this case of VAD where we are seeking a prognostic opinion with either documentation, evidence, results and X-rays et cetera, there may not be a requirement for somebody to be face to face to look at that evidence and made the decision about a prognosis.

K McNAMARA: I know there have been models or estimates of a number of people who might access VAD if there was this legislation. Would you have numbers that you think might be expected?

Dr BURGESS: Yes, we do. We can base ours on what we have seen from Victoria. Victoria was the first jurisdiction in the country to legislate voluntary assisted dying. At its peak now, there are about 300 patients a year in Victoria who access VAD. That is equivalent to about 0.6% of all deaths in the state of Victoria, so it is a small number.

If we translated that number to the number of deaths in the Northern Territory we would expect to see between 10 and 12 patients a year who would be accessing the VAD service. That would be the current state that Victoria has got to after many years of practice. We would anticipate a slower start.

K McNAMARA: In terms of equity of access and despite the low numbers, do you have a view of it still being an important healthcare thing for people to be able to access even if it is small numbers? Does it balance out?

Dr BURGESS: Absolutely. This is a valid and needed clinical option for patients. If we take the patient's view—I am sure you have heard from patients in this inquiry—they want choice.

Mr KERLE: We touched on just before the Commonwealth telehealth limitations. For the benefit of the committee, are there any other, either Commonwealth legislation or external, considerations that we need to take into account? One of our terms of reference is to provide, if the committee recommends moving forward, drafting instructions. What external factors need to be taken into account, more than the limitations of telehealth?

Dr BURGESS: I can speak to one. Clearly, funding is one. NT Health—it is well known and has been stated separately—is under significant cost pressures in a structural position vis-a-vis Commonwealth funding. VAD as a service, albeit low volume, would still have a significant cost impost on the Northern Territory health system. In terms of funding and doing this well and properly, we cannot do this within current budget because of the sensitivity issues and the need for us to have a system that is responsive to patient needs and timings, and also responsive to our clinicians as well and not to overload them with additional work without additional capacity.

Mr CHAIR: Given those limitations and the extrapolated numbers that you have on how many people might avail themselves of VAD service, is there any merit or wisdom to the idea of outsourcing this service to another jurisdiction where there might be more specialist capacity already set up?

Dr BURGESS: We have legislative barriers to do so. All VAD legislation is state or territory specific.

Mr CHAIR: Specific requirements, yes.

Dr BURGESS: That is right. As well, the training and accreditation requirements are all state and territory specific. It is a weakness of our Federation.

Mr CHAIR: We are trading in the realm of hypotheticals, as we all know, at the moment. We are essentially looking at a report with a model for how to proceed upon which we are looking at drafting instructions for a model Bill, perhaps. We are also thinking about model implementation in that regard.

I am trying to get to the crux of it here. We have a health system that is already under extreme stress with some limitations in relation to workforce and capacity deficits. We hear about palliative care repeatedly and the requirement for more to be done in that space. Can we afford a VAD service in addition to these other things?

Dr VELLAR: It is our view that we should have the opportunity for patients to have that autonomous choice. It is essential to Territorians to have the same access to the suite of treatment options as all other Australians have. It is for that reason that we feel it is an essential treatment choice for patients to go down that pathway. As part of the expert panel, that was a very clear directive from the community, just to be able to afford people choice.

The emphasis—we heard that before—was on the voluntary nature of this service. Sure, there will be an impost of funding implications for the department which would need to be considered to ensure that there is appropriate palliative care services to complement access to VAD. It should not be one way or another; it is essential to have those patients who seek palliative care services to access that pathway and for those who seek VAD to access that pathway. Of course, there is always crossover with those who seek VAD would not be refused clinical service from the palliative care service.

I think that is pretty clear within the expert panel report in that we considered quite extensive consultations with the palliative care team, Palliative Care NT, who really wanted to emphasise the fact that existing palliative care services are relatively stretched, and we are unable to provide those services to those in remote areas. In offering a new service we would ensure there is an expansion of palliative care services to also offer that choice to those people in rural and remote areas of the Territory.

Mrs CARLSON: Expanding on Dr Vellar's comments, with the Northern Territory being such a large area with a very small jurisdiction and logistical, clinical and cultural challenges delivering VAD in remote areas, is there any way of us being able to still deliver that or would a centralised model be maybe acceptable to initially start with, then placing some review timeframes to expand it as more and more people need to access, or as the population grows as well? Is there a timeframe that you would put in place for this to be reviewed on a regular basis as well? Sorry; there are a few questions in there.

Dr VELLAR: If I may refer to the report, it does provide some clear guidance around that. From the expert panel's perspective when we undertook those consultations and we established a model that was grounded in significant research from interstate models, international models of service delivery of VAD, it was felt that specific to the NT context there would be a pathway for legislative provisions, but the predominant pathway that dealt with a lot of the logistical and operational issues would be something that would be established by the VAD service itself.

Whether that sat within NT Health or an alternative would remain to be seen, but it was the feeling that overall we would look at having a standalone service which is able to account for managing some of the expectations of VAD, particularly around the cultural appropriateness of implementing VAD in remote contexts.

There was also consideration around an opt-in opt-out model for various remote communities so that we could have that option for VAD both in regional centres but also whether a fly-in fly-out model was required for remote areas for those wishing to access. That would be something that would be in an operational sense rather than legislating around any of those practicalities of implementing the legislation.

That was part of the challenge probably in discerning within the expert panel report what is operational and what is required within the legislation. It would be a perspective from the panel and my personal view—I am not sure about NT Health—to simplify the legislation so it is simplistic, and the bulk of the work would be required to be completed by the Department of Health in implementing policies and procedures to ensure that the implementation of VAD was culturally safe and secure.

Mr CHAIR: We have heard quite a lot of support for the idea of a standalone service. We are now starting to think through what that might look like in reality. NT Health has obviously paid some attention to implementation, has existing panels and has been thinking in this space for some time. What might that standalone VAD service model look like in practice? Do we have a bottom drawer model we can take a look at to help us establish whether this is a feasible pathway forward?

Dr BURGESS: I think the intention had been for that legislation drafting implementation committee to be combined in these early discussions for drafting instructions. We are looking for that authorisation environment through the legislation.

Operationally, the centralised service makes sense in terms of the medicines management, managing the medicine that is prescribed. Also providing navigators to help people navigate through the system was a key recommendation of that centralised service.

Critically, if I can speak briefly from the perspective of a remote GP, it is useful to have a service that can provide—I might make the initial referral but there is a conflict in the community's eyes, upon the person who is then involved in the administration, potentially, of an agent, at lest, with every patient. Hence, the role of a navigator or service coming in to help with the administration of the substances, arms length from the GP, can help have some clarity about the GP's role in the community.

That is an interesting observation and goes to Kane's point about protecting the fly-in fly-out service. We do not know what the demand will be in our remote communities. My hunch is it will not be high at the start. Most of our demand will probably be in our urban centres to start with. It goes to the Member for Wanguri's point about how this might evolve over time.

Other centralised functions include, in other jurisdictions they had a registry or a board-type format. If there is an appeal—for example someone has only been resident in the Northern Territory for nine months and not the 12 months—is there an appeals process? We need to have a function where we can consider cases which are outside the prescribed goal post at the start.

We also need to have a monitoring, evaluation and a quality improvement component to understand what these care journeys look like and how they can be improved over time. Those parts all can be centralised. I am sure my colleague, Dr Chin, can talk about our robust clinical governance structures that exist already in the NT Health. They would be able to oversee those quality improvements.

Dr CHIN: It is probably at this point useful to talk about the levels of centralisation and decentralisation that might be open as options.

In Queensland, the discussion has been about a decentralised model through health services directive to what essentially would be a health service comprising facilities the size of the Northern Territory—perhaps not in geographic scope but as in population density. Each of those health services would have many layers of checks and balances already for people who will see a specialist, a rural generalist or an obstetrician. They would not just be checks and balances at the beginning of employment—for example, where did you go to medical school, where did you get your specialist registration; how many procedures have you done et cetera.

It would not just be the types of checks and balances provided by AHPRA that allowed someone to achieve registration through them or from the college that provided that particular fellowship, but a whole set of internal checks and balances as well that goes on as part of the onboarding procedure and that would particularly rest on credentialling.

We have come to understand in safety and quality healthcare—obviously, NT Health is accredited by the Commission on Safety and Quality in Health Care has a robust set of standards including clinical governance standards and partnering with consumers—that internal checks and balances need to be at least as robust as the external ones.

These would include ensuring that the right person has the right skills, level of training, experience and continuing medical and other development to ensure they have the ongoing skills and keep up to date and maintain connections and networks with the appropriate community of practice, which is important in places like the NT where we might have one or two specialists operating a particular sub-specialist field of medicine.

Those kind of internal checks and balances means that when someone walks into an NT Health facility they can be assured—the public can also be assured—that the level of care that is being provided is contemporary, appropriate for the geographic location and capabilities of facilities around that individual and meets the particular needs of Territorians which includes—particularly here—aspects related to cultural safety.

K McNAMARA: Following on from that, in terms of the qualifications and levels of training, could you touch on the role of nurse practitioners in this. I know there are differences state to state. I believe we might have heard earlier that perhaps the AMA was not of the view that nurse practitioners be part of the initial consultations. Does NT Health have a view on the role of nurse practitioners in the process?

Dr CHIN: I can perhaps talk generally about our credentialling in processes and then come down to VAD. This is in the context where there have been large reports released nationally about unencumbering certain sections of the workforce to ensure that the right care could be provided by the right person in the right time.

Our credentialling committees are designed to be able to handle that, so we are moving away from specialists with particular fellowships to be at a micro level thinking about who that person is and how we can be assured that they are doing the right thing. That includes front loading things, making sure they have been through the right training and education and, at the end, making sure that they are part of a continuous learning environment, having the right and appropriate monitoring and evaluation processes.

In many other areas in health we are seeing a shift towards credentialling which is perhaps agnostic of the individual profession, but more specifically focused on the outcomes and safe experiences for individuals which is a credentialling approach—less focused on professional, less focused on fellowship, more focused on the skills, knowledge and attributes for that particular activity.

Mr KERLE: Dr Paul, I was about to ask a follow-up question to the earlier one, but you have mostly answered it. I will quickly ask it so that you can wrap it all up together.

We heard evidence earlier from the widow of Bob Dent who was the first Territorian who was able to access the previous *Rights of the Terminally Ill Act*. My understanding from that testimony is that the level of resourcing from the NT Department of Health at the time was three signatures and maybe an airfare and the substance prescribed, whereas now it previously was said there would be a substantial number of resources required, and you commented on the navigators that would be required. Can you briefly sketch out what would be required that would entail that investment of resources?

Dr BURGESS: The model you are talking about and what that would cost is a good question. To some extent that will be determined by the legislation. It is kind of a chicken and the egg—right?

When we talked about the navigators, I think it has been a common experience in jurisdictions that finding a clinician who is accredited and trained and who is a provider in a VAD service can be very difficult, particularly if English is not your first language. The navigator who is in a community or practice who knows who is who and who has what qualifications, skills, specialty and subject matter expertise is incredibly important to patients and their families who are already struggling with a lot of complexity and a lot of grief about their potential prognosis.

It is a little bit hard to nail down and say dollars and cents at this point. To sketch it out, the centralised functions come down to training, accreditation, medicines management and the appeals board. That is all person time. Additional FTE would probably be navigators, and they may be navigators who work in other roles as part of their day, but have this extended role when required, given that we have already given you an impression that the likely caseload is going to be low.

There is a significant up-front investment to set up those systems, but when those systems are running and people have their defined roles and have completed their training, I think the cost will be quickly absorbed into other sort of business units.

Mr KERLE: One of the things we have been looking at is other jurisdictions have a 12-month prognosis as an appropriate timeframe for eligibility for VAD. We heard evidence this morning from Wayne Wood who lost his son to Ewing sarcoma. His son was not able to use any of these options. He had to watch his son die in a terrible way. This may go to Dr Chin or whoever feels more appropriate.

The variability of diagnosis and the utility of having a hard-and-fast 12-month rule in a recommendation, given the variability of diagnoses—we heard from Wayne Wood that his son was given a number of weeks to live and he ended up dying many months later. We have heard the opposite; that people might be given a long timeframe and end up dying much sooner than that. What is the utility of a 12-month prognosis to access the facility?

Dr VELLAR: I guess the timeframe centres on the ability for those wanting to avail themselves of VAD and the ability to access it within a certain timeframe. That was the initial view of the expert panel in that timeframe of up to 12 months. It varies state by state. The ACT recently was of the view that there is no requirement for a timeframe, simply the diagnosis of a terminal illness.

For the NT, the view of having it up towards the 12-month timeframe was centred around the ability for the patient to be able to confirm the diagnosis and seek access to VAD, knowing that there are limitations in being able to access specialists or appropriate personnel to go through the approval process.

It was also in view of harmonising with other states and territories at the time of the VAD report so that we were able to ensure our legislation would be consistent with others so that a national harmonisation program with VAD could potentially be possible in the future. For that reason we stipulated approximately a three-year review of some of those legislative provisions so we could ensure that we remained consistent with other jurisdictions.

Mr CHAIR: Dr Burgess, notwithstanding the chicken-and-egg conundrum that you alluded to before, the reality of it is that we can all safely agree that the cost and resource impost to introducing a VAD service is more than zero.

We are aware that a small number of people will likely avail themselves of this service in the first instance if other data is to be extrapolated and transferred into this jurisdiction. We are all interested in equity of access and trying to work out how we can create a model that, as Wayne Wood put it earlier, creates an unobstructed path.

There is the sense from some that the 2024 report is overly complex. To my mind, it makes a lot of sense in many regards. We are trying to look at where we can improve it and where the more than zero should be targeted when it comes to the resource investment, if it is the case that we require extra investment.

I am particularly curious, Dr Vellar, to talk about palliative care services because, again, we are mindful that introducing a VAD service almost always requires a co-investment in increase in palliative care services. Can you at least give us a starting point on what our palliative care service set-up is like and what we might need if we are to go forward with a model that would reflect the 2024 model?

Dr VELLAR: Currently, the palliative care service operates in a manner that the hospital consultation services requires one specialist FTE, community consultant services which is also a total of one FTE and a hospice consultant that requires one FTE.

They are ably supported by a team of rotating registrars of which there are three and a junior medical officer who is in the hospice.

The limitations currently within the service essentially centre around remote access. They are extremely constrained in being able to deliver palliative care on the ground. There is current capacity to support remote clinics and GPs in those areas, but we envisage a need for an additional consultant FTE to ensure that remote service is ably supported from a medical perspective. That would also require a case manager in terms of a palliative care nurse who has expertise and advanced training in palliative care. That would be the bare minimum to improve. That would also account for the Top End and Central Australia to be able to expand palliative care services.

Currently, we are quite limited in what we can offer outside of the larger centres. That would be a necessary investment. We have seen interstate where VAD has been introduced that there is significant uptake in palliative care services at the same time. That has been shown in Victoria, South Australia and Western Australia.

When we look at the increase in access to palliative care—in Victoria, there is a 20% increase in palliative care referrals with the introduction of VAD—talking raw numbers, it would be quite small in terms of those availing VAD, yet existing service provision is limited. If we were to introduce VAD, it would be necessary to ensure that palliative care services are also expanded to be able to ensure patients have those options.

Mr CHAIR: Even if there is a modest expansion in those services to facilitate a modest uptake in this area, what might the standalone service look like in terms of partitioning from the remainder of the health service? This is a question that comes up for us repeatedly. We want this to be distinct from the healthcare system. Having said that we cannot invest in an entire service that is idle, expensive and has limited uptake. I am mindful that you have had implementation plans in place before. We are providing supplementary data now to many years of consideration of these issues.

From NT Health's perspective, what does the model look like for the standalone service? Where is it hypothetically located? How many people does it involve? It is a FIFO model? How do we get around telehealth?

Dr BURGESS: These are all really good questions. The pragmatics of this, because of the low case numbers, is a shared service delivery model. They will have people who work in a VAD team, maybe 0.3 and then 0.7 in another role. That is an FTE that has divided their time across multiple areas of work. That is not uncommon in the Northern Territory. It is a place where we wear lots of hats.

The fly-in fly-out that you referred to is a necessary encumbrance at the moment until we have resolution of the telehealth at a legislative level. We hope that in the time the legislation is drafted in the Northern Territory, there will be some progress on that issue that frees us up. You will be aware that the Commonwealth legislation overrides Territory legislation. We must observe that.

Perhaps the other element that we have not touched on is the navigation service. That is additional FTE. Those people are really important. That has come through quite strongly in a paper I have just reviewed—that is in progress—around patient experiences in Victoria, just because of the complexities of navigating a very large and complex system in Victoria and trying to find the right people. It is less of a challenge in the Territory, but we still have other navigation challenges in terms of language and culture, for example. That would be the other additional component.

Then the training set-ups, the medicines management—again, those are cost shared in terms of a pharmacist would have a role nominally in a hospital service and then some of their time could be devoted to VAD as well.

Mr CHAIR: Separate to that, we have practitioners on review boards. We have heard several times a palliative care specialist must be on one of those. We are trying to ensure that if we move forward, people have confidence in Chinese walls in the system to ensure that if an FTE is divided into people wearing multiple hats that there is still integrity in the system in terms of checks and balances, practitioners, people who are able to be conscientious objectors. Do we have the capacity to be able to subdivide those people?

Dr BURGESS: We already do. We are quite used to being in lots of roles and declaring our interests and following good governance on such committees and being very mindful of our participation in those discussions. NT Health has great experience in that by necessity.

K McNAMARA: The 2024 expert panel recommended an 18-month timeframe to be appropriate for implementation—say we get to the stage of having the legislation. Does NT Health consider that 18 months feasible for implementation of VAD if it was to come to that?

Dr BURGESS: I think we have some advantages in being the last jurisdiction in terms of learning from other jurisdictions that have gone before us in terms of implementation timeframes. I think it is feasible. The vision formally was to have the legislation, and implementation could be combined so that the processes could occur in parallel, lockstep. That is one option; the other option is to wait for legislation and then to start the implementation process, but 18 months, given the scale of the startup would require some investment at that time in the 18-month period in terms of setting up systems and training. After that I think it would be fairly smooth sailing.

Mr KERLE: My question is about safeguards around the substance. Obviously we do not want to put anything on the public record that is too sensitive, but my understanding is—what safeguards should be put in place to ensure the supply and storage of a VAD substance so that it is safe and accessible, and should these requirements differ from remote communities? Pharmacies and medical practitioners, particularly at hospital, routinely administer very strong painkillers, and the line between a strong painkiller and a substance may be very grey. What safeguards would be required in addition to the normal safeguards put around a strong painkiller like morphine, fentanyl and ones routinely used in a medical setting for a VAD substance?

Dr VELLAR: As you can appreciate and, respectfully, returning to the future, there is a very detailed chapter within the existing report which outlines the requirements and the legislative provisions that would be necessary to ensure safe storage and disposal of the VAD substance. That significantly aligns with all other jurisdictions ensuring very robust storage requirements and significant consequences if those practices are not monitored appropriately.

That goes back to our need to ensure that a centralised pharmacy to monitor these substances is necessary in implementing in a small setting. It also talks on the fact as to whether someone would like to avail themselves to self-administration of the substance versus practitioner administration, which would also dictate the manner in which the substances were stored and managed.

Dr BURGESS: I will add to that. The key role of a navigator in the system in coordination most likely with the GP in a community setting is to do a medication safety check with the family and the patient. We are very used to managing medication issues in that context in remote settings.

Mr CHAIR: Dr Vellar, you could be forgiven for being partial towards the 2024 report. Obviously, everybody in this town wears multiple hats. We are all aware of that. We are not seeking to usurp or scupper the 2024 report so much as to see if there is any places where it requires refinement where with the passage of time or with any of the additional consultation we are doing, we can identify, for example, any nooks and crannies that might be tightened up in that regard.

One of the things we are charged with regularly is why can you not take the Rights of the Terminally Ill Act 1995, scrub out 1995 and stick in 2025 and bob’s your uncle. It would be helpful to hear from NT Health’s perspective why that might not be an appropriate way forward or if indeed it is a feasible way forward.

Dr VELLAR: From a personal perspective, it is about balancing the expectations of the community and ensuring there are appropriate safeguards and checks and balances in places. That is part of the rationale as to why that report made those recommendations and, more importantly, that it aligned with other states and jurisdictions.

Since that report there has been an instance in Queensland where a responsible person—responsible for that substance—had taken that substance. There will always be issues that may arise in implementing this. It is about making sure it is safe for the community and the community can have the confidence in public institutions to protect vulnerable people. That is the rationale behind ensuring that we have checks and balances and legislative mechanisms in place so that those who are opposed to VAD are able to appreciate that there is significant thought and consideration about ensuring the rights of all of those members of the community are protected.

Mr CHAIR: Following on from that, is it fair to say that Australian jurisdictions have largely coalesced now around an Australian VAD model, give or take, and that the 2024 report reflects the standards broadly articulated in the Australian model for voluntary assisted dying?

Dr VELLAR: That is correct, with the exception of the ACT model which is probably more liberal than other jurisdictions. For example, in the NT context we reviewed some access issues about medication, medical practitioner qualifications and requirements. They were, from other jurisdictions, less restrictive so that it could ensure access. We were aware of the limited number of practitioners who may be available for VAD here, so we made contextual changes to our recommendations to reflect clinical practice on the ground here.

Mr CHAIR: The core part of this inquiry, as you would be aware, is for us to engage with remote communities. We are about to embark on that journey tomorrow and for the remainder of the month. A challenge for us will be to communicate to people out on communities that this is a voluntary service and distinct from the health service, particularly when we know that people have to wear multiple hats.

What more, if anything, can you tell us to give us insight or confidence regarding the separation of a standalone service from palliative care services and health services generally in the Northern Territory?

Dr VELLAR: With respect to remote communities, it was our view from the previous report that it required the potential for an opt-in opt-out model for those communities. There were community members who were of the notion that this is a completely foreign concept to them; it did not align with cultural values or world views about death and dying. We need to respect that. It would not be surprising if there is limited attendance regarding these matters, because it is, from a remote Aboriginal community perspective, quite a difficult subject to raise. It has been our feeling that, with regard to remote Aboriginal Territorians, there is the necessity to provide those protections through VAD and appreciate that. In our consultations we experienced a lot of pushback in remote traditional settings, whereas there were more relaxed views in urban settings.

From the view of NT Health more generally that talks to the need to have a centralised model that is culturally safe and ensures that all those practitioners involved in VAD have the requisite skills and knowledge to work with those in remote settings and, from a palliative care perspective, ensure that there is a clear separation.

We had issues in the past where a lot of remote Territorians were concerned about accessing health services, particularly where it related to VAD—or previously, the rights of the terminally ill—because it had a lasting effect on some community members. That was spoken about in our consultations. For that reason, it is essential that we ensure that this is a separate pathway and that NT Health is open and culturally safe and kind and compassionate in its care to open for the whole of the community, but certainly respecting the views of remote Territorians.

Mr CHAIR: In the nine months that the *Rights of the Terminally Ill Act* was operational, there were concerns from the outset that there would be lower uptake of health services by Indigenous Territorians in particular. Empirically that turned out to not be the case, according to some work done by NT Health at the time, as well as by the Senate inquiry that looked into the matter thereafter.

We would like to be able to give people confidence in the fact that if a VAD model was to be legislated, that it will not compromise NT healthcare in any other regard. Is that an undertaking that we can fairly make to Territorians?

Dr BURGESS: You can. There is some fear and uncertainty in my communications with Aboriginal friends in remote communities. It goes to the strength of having a standalone model and that it is not seen as either/or; you have both options available to you. That also helps the clinical teams on the ground to have a clear role definition for that community.

That being said, the clinical teams in remote communities are critically important to give important information to the VAD team regarding some of the social and cultural factors surrounding a patient and their choice.

Mr CHAIR: We have had great responses from a number of communities at the moment wanting to engage with us regarding the issues. A small number of communities have declined to participate. Do you have any advice, as practitioners out there, on how we might approach these issues, noting that there had been prior consultations taking place in this area?

Dr VELLAR: In our previous consultations, we encountered often very strong religious, moralistic views from communities which must be appreciated and respected. Where those views were quite predominant in communities, we only heard one side of the debate. It is important to ensure we are reflective of the whole pluralistic society so that we appreciate views from both perspectives. We encountered in specific instances very strong opposition based on religious grounds. We respect those views, but we need to cognisant of others in our community who have alternative views.

K McNAMARA: When you had those views expressed to you—the ability of conscientious objectors—were people who hold those strong religious or moral views on it comforted by the idea that people could conscientiously object? From a medical practitioner’s view, did you get any feedback on how they felt that was an appropriate check or balance for them?

Dr VELLAR: One of the challenges was, from both perspectives, we experienced significant opposition then at other times there was a lot of pro VAD. It was about trying to balance those views. The challenge with conscientious objection is taken care of by having a standalone model in enabling those practitioners or community members who do not want to access that service. Then they are not necessarily provided with that information. The medical professionals who expressed their conscientious objection made that clear. That was appreciated. That was part of the rationale for ensuring we had a standalone model so that those referrals could go in that manner.

Mr CHAIR: We want to ensure, of course, that people can provide informed consent to any procedures that might hypothetically happen in the future. The 2024 report recommended at least one of the VAD requests be in writing but not all of them.

We know literacy and numeracy is lower in remote Indigenous areas than in the rest of our urban centres. Is that an appropriate recommendation, do you think? We are aiming to try to make it a flexible process, but we also want to ensure safeguards in the process.

Dr VELLAR: That was a legal requirement to have it in writing and/or in some other way communicated by the patient as a legal mechanism. Again, that aligned with all other states and territories.

Mr CHAIR: Do all of those requests need to be in writing in other states and territories?

Dr VELLAR: Yes.

Mr CHAIR: The recommendation in the 2024 report was for at least one of them, but not necessarily both of them.

Dr VELLAR: Yes. Again, to cover off on some of those unnecessary restrictions that may occur in that context, but it still did require three assessments, essentially.

Mr CHAIR: Finally, from the consultations that were done in the past, which would have some interaction with NT Health as well, was there a sense that there would be uptake or consideration of voluntary assisted dying in remote Indigenous communities? Were there discussions or any clear sense that people might want to finish up on country in some communities?

Dr VELLAR: Overwhelmingly, there was limited views expressed about voluntary assisted dying from remote Aboriginal Territorians. Again, that aligned with their traditional world views. We did not have any clear directive about that, which is why we considered that opt-in opt-out model for communities.

Mr CHAIR: All the more reason for us to traipse around the Northern Territory for the next month and hopefully garner whatever views we can in that regard.

Gentlemen, thank you very much for availing yourselves on short notice and answering all our questions. We will, no doubt, have more questions in due course and may impose upon you for some written questions, if you like. There will still be an ongoing conversation we would like to maintain with you, particularly with regard to forecasting, foreshadowing, dreaming up what implementation frameworks and models might look like because those questions are becoming more and more real for us.

We appreciate, as a committee, that there is broadbrush, in-principle support across large swathes of the Northern Territory for legislation in the VAD space. What that looks like in practice, if it will not be the rights of the terminally ill, is the question we are trying to provide some definition to.

On that note …

Mr KERLE: Sorry; one final thing. Do we have a copy of the navigator report from Victoria you were talking about, Dr Burgess?

Dr BURGESS: That is an academic journal article that is going through peer review. It is not available publicly. I will share that when it becomes published.

Mr CHAIR: On that note, once again my thanks on behalf of the committee for appearing today to speak with us on this important matter.

The committee concluded.
