The committee convened at 1.06 pm.

INQUIRY INTO VOLUNTARY ASSISTED DYING
Tennant Creek Hospital

Mr DEPUTY CHAIR: I respectfully acknowledge the traditional owners of this country and pay my respects to elders, past, present and emerging. My name is Matthew Kerle. I am the Deputy Chair of the committee and given that the Chair is unwell.

Mrs CARLSON: In your hospital.

Mr DEPUTY CHAIR: Thank you for looking after him. I am the Member for Blain, which is an electorate up in Palmerston. This is my colleague.

Mrs CARLSON: I am Oly Carlson, the Member for Wanguri, the neighbouring electorate to the Royal Darwin Hospital.

Mr YOUNG: I am the Member for Daly. I represent the communities of Wagait Beach, Dundee, Daly River, out to Wadeye and down to Pine Creek.

Ms SMITH: That is a big footprint.

Mr YOUNG: It is, yes.

Mr DEPUTY CHAIR: We are recording and would like to use the transcript of this for the record, which means the transcript will be public on the website. Parliamentary privilege applies to this discussion; however, if there is anything you want to say that you want to be kept private and redacted from the public record, please let us know and we will do that.

Do you mind giving your name and title for the record?

Ms SMITH: I am Ruth Smith[redacted]. My background is critical care, and my post-grad is in ICU. That is my main specialty of expertise.

Mr DEPUTY CHAIR: Before recording started, we were talking about your role in the rollout of VAD in New South Wales.

Ms SMITH: When New South Wales was looking to roll out VAD, they also had a stepped-out process. They included, quite heavily, ICUs within New South Wales for that, sort of identifying that nurses and doctors in the ICU sector saw patients or were in that demographic of when patients may be faced with life and death decisions, and they may express a desire and ask if this was an option. That is why they pulled in ICU-trained staff.

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Personally, before I worked in critical care medicine, I had the opposite view to VAD that I do now. I used to be against it; however, the more I saw of disease processes and the more I saw of suffering I became all for it, to be honest. In New South Wales there were extremely clear guidelines on cognitive ability. You had to have full cognitive effect to be able to make this decision. I have always been a little bit 'Hmm' about that because it just cuts out this whole cohort of people with dementia and Alzheimer's and all that sort of stuff who may have been able to articulate their hatred of that sort of disease process, but they cannot enact it now because they are not deemed cognitively sound.

Mr DEPUTY CHAIR: On that specific one, do you have, from your clinical experience, any recommendations on how a future VAD system in the NT could manage that cohort, whether by expanding the timeline so they could go through the approval processes while they are fully cognisant?

Ms SMITH: I think that is a really difficult one. [redacted] How you capture the dementia cohort without them opening up the whole quagmire of coercion and like ulterior motive sort of things if there is financial gain to family, I do not know. [redacted]

Mr DEPUTY CHAIR: That could potentially be something that is part of a review if it is recommended to be enacted.

Just to be clear, our role as a committee is to write a report on VAD. There was an expert panel last year, so we are going out doing consultation in remote areas which is probably just to complement what was done last year. Then we write a report based on our findings and then that goes to the Attorney-General and the government and they decide what they want to do. If that was the state in the NT it could be something that is part of a review afterwards to say, 'Let us look at this cohort and what can be done there'.

Ms SMITH: Yes, sounds good.

Mr DEPUTY CHAIR: Do you have any other feedback, comments, about the rollout, access to VAD?

Mrs CARLSON: You been working in this hospital. Are there any safeguards that we would need to use with cultural differences, cultural considerations?

Ms SMITH: You would need to bring on Aboriginal liaison about that. To be honest, I think in this area it is not going to be your Aboriginal population that want to enact it because there are cultural ramifications surrounding death that are a little different to a Caucasian perspective. [redacted]

[redacted]

[redacted]

Mr DEPUTY CHAIR: In terms of the demographics of the local area, so there are a cohort of people who do retire here who are not Aboriginal or Torres Strait Islander people, and they might be more interested in it.

Mrs CARLSON: Would they more aligned with the end process? It would be more at their home rather than in the hospital setting.

Ms SMITH: [redacted]—I think the key issue for this particular area is not how people, where people, do it, but who is going to have the training to be able to administer those medications. I do not know what the NT is looking at, but it is not just a case of there you go, there is the medication, off you go. It is quite a safeguard process, particularly when it comes to the IV.

The other thing as well is that, in New South Wales, the process for the person to pick up the oral preparation—there was a process for them to pick it up but then there was also quite a stringent process for that be returned to the pharmacy if they did not use it. In this particular demographic, that might collapse a bit and become quite problematic.

[redacted]

Mr DEPUTY CHAIR: There was a coronial in Queensland. There was a couple and one of the couple was eligible for VAD and was issued a self-administration dose. Then they contracted COVID and went into hospital and alleged that they chose to take an IV VAD at the hospital which meant there was a gap in the legislation where they were able to get the IV dose while the oral self-administered dose was still at home.

After they passed, the partner who was not eligible for VAD became quite distressed and self-administered that VAD dose. We will be taking note of those findings in our report. Basically, it boils down to you can only have one dose at a time. If they want to change, then the other one has to be returned, and there has to be strict controls regarding that.

Do you have any comments on location? We had a lot of testimony regarding cultural concerns about places where people die. If people were to use VAD, can you comment on is it appropriate? Where would it be appropriate? At someone's home? At a hospital? At a health precinct? Or definitely not at a health precinct?

Ms SMITH: [redacted]—your staff cohort may not be comfortable with that happening, but then with cultural considerations of place, it might actually be where people want to enact it because they do not want their home to have that connotation, especially if they have living family members who will remain in that home post their death.

Mr DEPUTY CHAIR: One of the considerations might be finding a suitable location. We understand that there are cultural practices when someone dies, like, if it is a cultural person. Even if it was a non-Aboriginal people who were in Tennant Creek using it, if they chose to do it at the hospital then Indigenous people might have concerns. It might cause cultural safety issues.

[redacted]

[redacted]

Mr YOUNG: Do you have palliative care services here at the hospital?

[redacted]

[redacted]

[redacted]

[redacted]

Ms SMITH: We do have a palliative team that comes once a month to give consult, [redacted] to, the best of our ability we try to emulate palliative practices and palliative care models. [redacted]

Mr YOUNG: With that palliative care service that is provided here if someone is wanting to go, say, back home or on country out of the hospital, especially Aboriginal people, do you see a lot of the cultural decision-making happening in the hospital and with the nurses themselves and, if so, how does that look?

Ms SMITH: [redacted]–Aboriginal people do not want to die in hospital. We will get them home [redacted]

[redacted]

[redacted] unfortunately, sometimes people must die within the hospital setting and outside country. But to the best of our ability we do what we can to make that as culturally appropriate as we can, [redacted]

Mr DEPUTY CHAIR: Can you comment on the return to country bit there, [redacted]

Ms SMITH: Aboriginal people who are clearly dying or palliative patients, they do not want to die in hospital, so we will absolutely facilitate, [redacted]

Mr DEPUTY CHAIR: How far does your reach range? If someone from Galiwinku, for argument's sake, was here and in that situation—or is it primarily for the people sort of in the catchment around Tennant?

Ms SMITH: Our responsibility is within the Barkly region. To be honest, in my time here I have not been involved in a case where we had someone become palliative who was actually from Galiwinku or Elcho or Nhulunbuy sort of region.

Mr DEPUTY CHAIR: Outside the Barkly, yes.

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Mr DEPUTY CHAIR: One of the things that we are interested in is administration, so self-administration, but someone has to bring the substance out and facilitate—give it to the person. Do you have any ideas for us around the appropriate level of that person? Do they need to be a doctor? Could it be a nurse practitioner?

To be clear, there are two kind of final models on the table, so physician administered—IV—or self-administration which would be the oral preparation. Looking at the stats from other jurisdictions, it seems to be a rate of 30, 30, 30—one-third IV administered, one-third self-administration and I cannot remember what the third was. Were they returns?

Ms SMITH: Returns, yes.

Mr DEPUTY CHAIR: Say to start out with, the categories have got S8, the highest level, the drugs will be used. Is that something that an RN would be normally …

Ms SMITH: For an S8 drug, you need two RNs to sign off. [redacted]

[redacted]

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Mr DEPUTY CHAIR: From looking at other states, the number of people who die is—I think is 1% of deaths or something is the number. We have a lot more untimely deaths here. The population who would likely use it, we would be looking at numbers between six and 10 approximately per year, and the majority would probably be in the major metropolitan areas. But we want it to be possible. We want equity. Someone who is living in Tennant Creek and wants to access that service, ideally, they should be able to.

[redacted]

[redacted]

[redacted]

[redacted]

Mr DEPUTY CHAIR: The more that we can open up so that the patient has the choice.

Ms SMITH: Yes.

Mr DEPUTY CHAIR: A lot of people want to have their family and friends. We hear that they have a big party. We had this really great submission on the website where they had a big party. The guy was an avid shooter in Queensland, and he went and shot a beer can at a 1,000 metres. They had a big family party and then at the end of it, he took the stuff and passed away. That is a good way to finish up, which is ultimately what we are after. We want to help people to finish up well.

Ms SMITH: The way that they decide.

Mr DEPUTY CHAIR: Yes. Any other questions that we need to make sure we ask? What about interpreters and Aboriginal liaison?

Ms SMITH: [redacted] —we have 16 languages spoken throughout the Barkly region [redacted]

[redacted]

[Multiple people speaking.]

Ms SMITH: Hello, how are you? I am just finishing up, so good timing. I will leave the room, and you can have the hot seat.

Mr DEPUTY CHAIR: Have a seat. Before we finish I have a question, if I can, regarding withdrawal from treatment. We have heard a lot of evidence regarding people at end-stage renal failure and stage 4 cancer. For various reasons, they may not want to choose VAD, which is a positive action to ending the life. They may, instead, just choose to withdraw from treatment, go back to country and pass away there.

[Multiple people speaking.]

Mr DEPUTY CHAIR: When we talked about this in Alice Springs with the palliative team there, this idea of withdrawal from treatment, they all opened their eyes and made a comment that it would be a real cultural shift but a good cultural shift. Do you have any comment on …

Ms SMITH: I would love to see that done better [redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

There are a lot of people who—for example, when you are talking about communities, where we just spent a lot of time, the testimony has been that they are probably not really going to be taking up VAD in any great numbers. What happens frequently is that when people are sick of the renal care or the medications are not really working and they are suffering a lot, they go, ‘I just want to finish up’, and then are travelling home to family.

We heard some really good testimony in Ngukurr about people coming home. They have a little clinic there, so they would get a proper bed. They would go to a place near their family and rest under a tree. All the people would come and gather round and do all their cultural things. The person would get pain relief during that process and then the person would pass away in the course of time.

Ms SMITH: I think if there is one thing that is, from a training perspective and training new doctors who are coming into the NT, it does not rest on the person whether or not it is appropriate to withdraw a treatment; it rests on family members. So, doctors go to family members and they say, ‘We could do this, this and this or this. What do you want to do?’ That family member does not want to carry the weight of choosing death because that could come with retribution towards them. But if the doctor goes to the family member and says, ‘There is nothing else we can do. We need to enact the process of allowing this person to die’, then that person, will go, ‘Okay’.

White doctors—Caucasian doctors—are not taught this. They come in from the east coast—Coming from an east coast background the decision to live or die rests with the patient; [redacted]

[redacted]-We need to train our doctors to approach it differently, to know who it is who has that decision to accept the diagnosis and to tell the person, ‘For this person there is nothing else we can do’, and let it be; do not give them options, because they will always take the option if given it, because they do not want that retribution.

[redacted]

[redacted]

[redacted]

Mr DEPUTY CHAIR: Thank you so much. It has been really informative; we appreciate it.

Ms SMITH: That is good; thank you.

The committee concluded.