INQUIRY INTO VOLUNTARY ASSISTED DYING
Palliative Care Team - Alice Springs Hospital

CHAIR – Dr Tanzil RAHMAN: Hello everyone. I'll just check that our team is all good.
Welcome and thank you first of all, all of you for taking time to meet with us today.

Before we say anything else; on behalf of the committee and the staff we want to acknowledge the traditional owner of the country that we are on and pay our respects to elder's past, present and emerging.

We are grateful to be here and grateful to have the opportunity to hear from lots of people including yourselves. Today in a hospital setting but recently a lot of it has been out in remote communities.

My name is Tanzil Rahman I am one of the 25 Members of Parliament I am the Chair of the Legal and Constitutional Affairs Committee I am here today with two of my colleagues.

Oly CARLSON: I am Oly Carlson the Member for Wanguri, the suburb is actually next door to RDH.

Matthew KERLE: My name is Matthew Kerle the Member for Blain, so I oversee Moulden, Woodroofe, Bellamack in Palmerston.

CHAIR – Dr Tanzil RAHMAN: And two of my committee members can't be here today; Kat McNamara the Member for Nightcliff and Dheran Young the Member for Daly also on this committee.
Also, today we have Georgia, Katie and Caroline from the Department of the Legislative Assembly who have been helping us to do our job along the way as well. So, they are going to be here today recording this meeting. So, before I say anything more on the recording situation, we obviously would like to use this information as part of the testimony that helps inform the report we are going to write. If there is anything that you want kept private or you speak about in-camera or in-confidence or that you want redacted, essentially, please let us know and then we will of course respect those wishes.

The more we obviously can learn from you, the better, in terms of being able to inform the report that we write.
It is also important to say that this is a formal proceeding of the committee, so all the protection of parliamentary privilege apply as well.

I might just get all the names and we will just do a quick one for the audio, if that's Ok?
So, if you wouldn't mind starting with your name and your position.

MEMBERS of the Palliative Care Team: My name is Fred Meegle I am a clinical nurse specialist working in community palliative care. I am Sharon Clarke I am a clinical nurse coordinator working for palliative care. I am Anne Ryan I am the unit manager for community palliative care and the community palliative care facility. I am Linda Hauralli I am a registered nurse working in palliative care. I am Janet O'Brien PCA for palliative care. Chris Sanderson I am a specialist doctor in palliative care.

CHAIR – Dr Tanzil RAHMAN: So that is the palliative care team. We have got all palliative care today, great!

Matthew KERLE: Awesome!

CHAIR – Dr Tanzil RAHMAN: Ok, notwithstanding that it's palliative care we always say upfront that we know it is difficult talking about voluntary assisted dying and so if people want a break or they're feeling uncomfortable or distressed in any way then we always encourage people to let us know so we can take a break.
We also as a matter of process have support services available; I'm preaching to the choir obviously I realise you are a palliative care team.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I think we can cope. It's Ok part of the job.

CHAIR – Dr Tanzil RAHMAN: Well quite, but as a matter of protocol it is fair for me to say that upfront.

Alright we have tonnes that we want to ask you about and we want to hear from you about; I will just set the scene a little bit just to make sure we are all on the same page about where we are at for anybody who is not across the great history of voluntary assisted dying in the Northern Territory.

So in 1995 The Rights of The Terminally Ill Act was passed by a government essentially; that provision for voluntary euthanasia under a specific format. In 1996 that law was essentially disallowed by the Federal Government on the basis of territories not being able to make euthanasia laws. In 2022 the Federal Government repealed that ban essentially allowing the ACT and the Northern Territory to also make voluntary assisted dying laws. Since 2017 Victoria first and now every state and territory has passed a voluntary assisted dying law of some form; broadly consistent with what we are now calling 'The Australian Model' albeit there are some minor variations within all of that.

The former Labor Government commissioned this independent expert inquiry report which came out last June 2024 which proposed a model for how voluntary assisted dying might work in the Northern Territory. In May we were tasked by the Attorney-General of the new CLP Government to look into that report and to examine the model and to do five things broadly. 1) to write consultation paper regarding the issues that were most pertinent in that, which were done. 2) to go out to remote communities as much as we possibly could within a fairly time limited period to try and get the views of people on country about voluntary assisted dying and issues surrounding that. 3) & 4) to look at other Australian models, to look at VAD specific challenges for the Northern Territory and to think about whether or not a model could function for the Northern Territory given its unique demography, economy, circumstances, burden of disease, etc etc.

And then finally if all of that checked out to then provide drafting instructions for a model legislation on VAD. And so all of that work and the report essentially is; our job is to do nothing more than to write a report present it back to government and then for government to consider how they want to move that agenda forward; and we will be reporting back to the house in September and then we will see where things go from there.

So, to date we have had hundreds of submissions coming in, in written form; including one of course from the Alice Springs Hospital which we are familiar with.
It will be useful to just note; were all of you involved in that submission, were some of you?

Dr Chris Sanderson – Specialist Doctor Palliative Care: No. Just from the heads of the department.

CHAIR – Dr Tanzil RAHMAN: Yes. So I saw heads of department; I wondered how far down the food chain it might have been.

Dr Chris Sanderson – Specialist Doctor Palliative Care: The heads of all the departments, the medical heads of all the departments

CHAIR – Dr Tanzil RAHMAN: Ok so we have very developed interest??06:24 knowing that it digresses from this model in a number of ways, it also ------------06:30 broad-brush support but also raised some very specific challenges which will be really good to talk about at some length.

We --------------06:37 in the last sittings of parliament in July which is essentially explaining the process we have been following and also our consultation choices for going out bush. In terms of going forward, we will be wrapping up our consultation work and the written submissions by the end of this month, then there will be a parliamentary sitting at the beginning of September where we will have a look at what we have got and then go from there essentially.

So whilst our remit is to look at this report, this report and VAD specifically; VAD as we know and as the report identifies and sets extensively with palliative are, with aged care, with interpreter services in this place. So understanding the full tapestry of the health set-up here is extremely important for us, because whilst we know that the uptake for voluntary assisted dying within Indigenous -----------7:27 might be quite low we also still need as a matter of equity to be able to provision for people who might want to choose that if they were the one to choose that.

And so there was a tension??7:37 there of course, in terms of being able to provide a service that is accessible and affordable and viable but at the same time not wanting to promise something that we know is not going to be able to happen.
So anything you can do to fill in the gaps for us in and around all of that would be very helpful. So I might by stopping there just to allow you all to say a little bit about how you feel about the VAD set-up or if you had any knowledge of this, and then we might go from there and start digging under the hood a bit. Does that sound Ok?

Dr Chris Sanderson – Specialist Doctor Palliative Care: We're a team I don't necessarily go first but, I think in this case full disclosure I was on the advisory panel; so I was one of the expert advisory panel members probably the only one actually working and based in Central Australia, so I kind of took that responsibility fairly seriously.

I think voluntary assisted dying has to come here there is no way we can be the only jurisdiction that doesn't have it. Particularly given our history and it's very important we get it right for us because we deal with dying people all the time we have these conversations with people. We don't hear a lot of people actually requesting VAD but it does happen periodically; not much amongst Aboriginal people almost never in my experience in fact.
But none the less there is definitely, and having been on the panel I know in terms of public discussion there is a big sense of like; 'this has to happen here'.

So for us we have been waiting with bated breath to hear what is likely to come what kind of model that government is going to want to support here.
We do have a lot of thoughts I guess about concerns about what may be the unintended consequences if we don't do it well. Fred in particular was here when the first legislation was put through and he will probably talk about what that was like and how that played out.

So look we support people who want and are eligible for VAD to have access to it and we will take them on as our clients and look after them as our patients. But I think what is important for us in palliative care is that we don't get identified as the VAD providers. Because what that does is it means all the other people who don't want VAD and are scared of palliative care and are already are often freaked out and anxious about coming towards us anyway; hesitant, frightened, they think our medications are killing them; we deal with that stuff every single day it has always been an issue in palliative care; "What is that medication for?" "What did you just give my mother"?
And here for many Aboriginal people in particular there is a real mistrust or anxiety to health care, they don't always feel that safe in hospital with doctors.
So we have built a service that has become very acceptable, well known, I would say "popular" but they don't come because they want to come but it is something that families will readily use.
And so we have a real concern that the way that is implemented here needs to protect what we have already done and the access to that service for people who are going to be using VAD or wanting VAD.

So that is our big worry I think we are going to have to be really creative about how we do things here because we don't have many clinicians who would probably like to be VAD providers. And we don't have many alternative options; like there is no private hospital here there is no where you can hide the process really, within the health care system.

Matthew KERLE: Do you have any private GP's in Alice?

Dr Chris Sanderson – Specialist Doctor Palliative Care: There are private GP's in Alice they are a small and dwindling number who are incredibly under pressure.

I think during the advisory panel process I identified one who might be willing, only!
Some of the newer registrar' who are coming through some of them might find it acceptable. But for people who work in a remote setting as well as in town; some of younger GP's might they might work partly in ACCHO (Aboriginal Community Controlled Health Organisations) and partly in private.
If they're identified with VAD in the ACCHO setting that is going to be very disappointing…

Matthew KERLE: What is ACCHO?

Dr Chris Sanderson – Specialist Doctor Palliative Care: Aboriginal Community Controlled Health Organisation; so congress or… so people who work across those two sites it's going to be quite hard. I think in a decade it will be different but certainly for I think the first five years it is going to be quite challenging as this gets socialised in our community.

We are a very unique and special place here, very special.
But we deal with a lot of dying people and very tragic, untimely, frequency of deaths in our community. It is very different from anywhere else I have ever worked.

CHAIR – Dr Tanzil RAHMAN: I have got a lot of questions for you, we have got an hour…

Dr Chris Sanderson – Specialist Doctor Palliative Care: But I'll shut up so that other people can talk. So I've said my bit for the moment I'll let everyone else …

CHAIR – Dr Tanzil RAHMAN: We have an hour so we have got a bit of time. Let's just go around the room I think.

Linda Bray: I think we will pass on to the clinical team.

CHAIR – Dr Tanzil RAHMAN: Absolutely, sure.

Linda Hauralli: Well I'd just like to say I am totally for VAD I think people should have an option. I am also aware that the cultural significance around that will be; I would assume we would have to tread very carefully because…

Palliative care is a small unit so of course people are aware the public know, have seen us in there and for myself, I wonder where would this happen because I want to able to walk into work and still feel that it's a safe space for those that might not choose to take there. But also I don't want other people not coming to us now because; “Oh they do it there” or “There is that nurse over there, she does it too”
So I am kind of ‘Yes’ for it but where would this happen is a big thing for me and the trust around that is huge, especially looking after this community. I think that is one of the major things to me and the safety around it.

Matthew KERLE: Thank you for that.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Hi. I think my main concerns are for the community; VAD in communities. Currently we have two nurses that cover the 1.6 million kms they don't go to communities that often, they physically can't do…

Matthew KERLE: They would if they could.

Linda Hauralli: We have been out there.

Anne Ryan (Unit Manager - Community Palliative Care Facility): So I think communities is going to be a very difficult situation. The nurses in clinics come and go they are only a few weeks and go…
Matthew KERLE: Yes. That's what we have heard.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Occasionally you will get a nurse who has been out there for 20-years who will know them.

CHAIR – Dr Tanzil RAHMAN: But there are few of those, yes.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Yes. There are very few of those.
And as far as doctors go, most communities once a month they will see a doctor and they may not be the same doctor each time so there is not that consistency.
There is also that fear out in communities, I have worked out there for a little while and I have worked in here so I am just speaking on what I have seen.

The decisions made about that and the Aboriginal people and I am sure you have heard from them exactly! But every decision that is made in the palliative care facility is by the whole family there is massive amounts of people. So the concerns for payback, wrong decisions being made, something going wrong and then next thing someone is getting payback, someone is getting the blame. It can be a very dangerous situation very complicated and just the resources in community; there is nowhere no resources or services in community to look the aged care in community. So end of life care is very difficult.

When we send someone to die on country it is quite a complex and ------------- 16:04 it is quite complex getting them out there and quite often it doesn't happen because the services are not there, the support isn't there so they have to come with us to die.
So that is probably my concern, the actual in community VAD I think it would be very tricky out there and I am sure you have spoken to the ALO's who have given their ideas and what happens out there.

CHAIR – Dr Tanzil RAHMAN: Yes.

Matthew KERLE: Yes.

Anne Ryan (Unit Manager - Community Palliative Care Facility): So I am happy for that. I think it needs to come, it has to come we need to have VAD here. But like you said; it is how it is set-up.

CHAIR – Dr Tanzil RAHMAN: Yes.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Personally I think in Alice Springs it will be in their own home.

Dr Chris Sanderson – Specialist Doctor Palliative Care: And that should be what we are aiming for.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Yes. That is what we are aiming for.

Dr Chris Sanderson – Specialist Doctor Palliative Care: That should be the goal.

CHAIR – Dr Tanzil RAHMAN: That's good and the is obviously consistent with the position in the Alice Springs submission about not wanting to allow VAD services to happen: to have them on hospital premises, which is a unique position that isn't expressed if you like, in other states and territories.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Could I also add, our palliative care facility is a bit different to a lot of the city ones. I know they are doing it in Sydney, places like that they have go special areas and special rooms set-up.
But a lot of those people will only accept patients when they are about to die, they have got to be dead within two weeks or one week, we don't have that.
We have patients constantly rotating through our community; they get there unwell they come in here we give them a tune up a bit of pain medication sort them all out so they can go back home for a while, and then they keep coming back. We are very different they can be quite long term our patients, they are not just here for that end of life few days.

CHAIR – Dr Tanzil RAHMAN: Lets go around the room before…

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): I have to say I am an advocate for VAD as well and personally I would be happy to be a nurse involved however I totally agree with our mob here; we could not do it within our facility and I do not believe any of our nurses could do it either. So while I am a part of palliative care team which I certainly don't want to leave, I could not be the nurse doing it.
And the places that could happen is in the home or whether it's in a motel or somewhere else but would have to be a private nurse and a private GP. There is too much mistrust out there as well, not a lot but it is out there.

We call our palliative care facility 'the comfort house' but I have heard it being called 'the death house'; saying I don't want to go to that death house people die when they go there.
So if we had VAD that would just exacerbate that.

CHAIR – Dr Tanzil RAHMAN: Ok. That is good to know as well; spaces are important.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): Yes. Where it happens is very important and we couldn't be involved.

CHAIR – Dr Tanzil RAHMAN: Fred?

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): As Chris said; so I started here in 1995, 30 years this year.
So at that time around The Rights Of The Terminally Ill Bill that was just coming into fruition and one of the big issues we had to face was unfortunately the media started picking up on palliative care and euthanasia in the same sentence which caused a major problem for us at that time. And it took us many years to actually move past that for people; and luckily medications have changed so it has been easier, especially to get people back out to remote communities to pass away on country.

So using things like instead of syringe drivers, pumps and medication under the skin; being able to use patches and drops and doing things like that so being a little bit more innovative about looking after people in that way.
The other thing was a lot of the misinformation that was out there and dealing with that at that time; places like Tennant Creek Hospital the impact on that the numbers of people turning up for immunisations and treatment actually dropped away, they had to declare themselves a euthanasia-free zone because of the impact of what VAD would mean, in that way.

So there are a lot of unintended impacts on service providers which we have heard about and the dynamics of actually looking after people when they are dying and the fear that that can illicit can't be understated; especially for the smaller areas. In 1996 when the ROTI Bill was active four people were euthanised up in Darwin. It was never actually mentioned I think outside of Darwin other than people requesting or talking about it, to my knowledge, there was never a request over actually being done here. So from a provider point of view and I had to soul search about what would be my role in that and I attend Church I am an active Christian; for me I was willing to actually sit and hold somebody's hand I would witness but I wasn't prepared to deal with medication and actually be part of that active admin part in that way.

So how do we reconcile our roles in this and it is a very individual thing; so how do we protect the clinicians? How do we look after the people that are there and as Chris and Anne and the other guys have said; supporting this and I have no doubt and doing the work we have done witnessing the people that we have helped to die and their families there is… I can't argue with VAD I have seen people who; it hasn't been an experience that you want to witness and I can't argue against it in that way.

Reading some of the submissions has been very enlightening as well, it is in a very passion filled sort of event. But the two things that I do want to emphasise is that about not lumping palliative care with VAD it needs to be supported and it needs to be a good alternative; having the services there for people so they don't have to take VAD as a last resort.
But also supporting the clinicians who are going to be caught up in that.

CHAIR – Dr Tanzil RAHMAN: Can I actually just say a couple of things before we continue on?

So most of you are familiar with the sort of model and what is being proposed here given that sort of set-up you have got; we are also aware that there are 1400 odd medical professionals in the Northern Territory, per capita that is actually higher than the rest of the country like 5.2 versus maybe 4.something else for the rest of the country. But we understand the burden of disease and the geography and demography of the Northern Territory means that actually we could use a whole lot more of everything! And we know there are capacity deficits in that regard.

Everybody is enamoured of the idea of a stand along service to compartmentalise away from seniors??24:32 for that reason. But by the same token there is a contradiction here where the Chief Health Officer and the Health Department when they testified to us said, and I am just going to read this out specifically: "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 .3 and then .7 in another role that is an FT that has divided their time across multiple areas of work. That is not uncommon in the Northern Territory, it's a place where we wear a lot of hats".

So we know practically speaking it is very hard to figure out how you would extricate the health care system from the palliative care system from the VAD system.

So where we are at with that at the moment is trying to understand in order to protect clinicians, conscientious objectives, people who may not want to be practitioners but would have to think about stand alone governance to allow people who want to be an active part of the process to choose to be part of it and if they don't want to, to be to withdraw from that as well. How does that sit with you?

Dr Chris Sanderson – Specialist Doctor Palliative Care: Stand alone governance is probably exactly the right way to think about it actually. Because sometimes it will be the same people; people who can find a way to divide their job that's not going to harm the ability to work with people. I know of one of our [VMO] consultants who probably would be willing to do that work when he is here. I think the way he works, he probably could do it. None of us probably the GP's will struggle nobody who works in ACCHO could probably be able to divide themselves and have it be like a completely separate identify .

So we will have to find those people who are willing and able to do that. I separate governance model and a separate kind of identity and I mean, in some ways that is about the look of the thing and the way it is publicised and promoted; it's like what is the phone number? What is the office? How do I get it? It is somewhere else, it is not here.
The information about how to do that is here, it is freely available but it is somewhere else.

I think for Central Australia the other thing is we have no idea of what the demand will be so it is really hard to know what resources to look in.
And I think ultimately it is going to end up like kind of a pop-up service, which is sort of how we work too really. Because like wise sometimes we will have three or four patients in a community and then we will have no one there for two years afterwards.
So we are there, we love them up, we do our job when we are needed and then we're not in the faces the rest of the time, but then know how to get on to us. So in a way it is a pop-up approach so there is the flexibility for us to pragmatically figure out what people need, where they are, how to help them with access to good local knowledge. But separately governance, separately identified, I don't think we need a big office in town I don't think we need to spend that kind of money. But there is probably somewhere that, if the navigator comes to town this is where they sit, but it is not in the hospital and it is not in the palliative care service.
We can practically pragmatically help you solve those problems, I think.

CHAIR – Dr Tanzil RAHMAN: Ok, so when we have gone out bush in particular, we know that there is initial resistance to; "I don't want that needle, that is not for me" sort of thing, right? But once we found the sequence of words of choice and help to finish up we got a lot of nodding heads in a lot of regards; and that's when people started talking to us about; you would rather not have loved ones pass away in Darwin, Katherine or Alice Springs Hospitals even how great the palliative services are, but to able to finish up on country if they can.
Now, there is a tension there between the fact that we know that it is difficult to provide service provision out there for people to finish up well.
This is the pointy end of the stuff, right? So this is what I am very curious to know as a palliative care team how could we provide people more choice and help to finish up on country?

Dr Chris Sanderson – Specialist Doctor Palliative Care: I am going to hand over to Fred he is our community group of great excellent.

Oly CARLSON: With a very small cheque??28:48

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): Very small. And this is the problem we need service providers, carers out there…

Dr Chris Sanderson – Specialist Doctor Palliative Care: Flexible. Like a little flying squad kind of thing is really what it needs.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): Yes. I mean it is interesting the Federal Government is about to release later this year; The Palliative Care $25k for three months when people actually die in their home in that way, how do we make that work when we have got no carers? Yet these are the practicalities of keeping it there, we have a little bit of work with Purple House and they have got a … bus
But the practicalities of 'how do we just get people home'

Anne Ryan (Unit Manager - Community Palliative Care Facility): So physically to get them home care and support for the family to help them look after them when they are there. Because it's you know, that is something that you are meant to learn to do.
In town when someone's dying we coach them a lot; we are in and out we are helping them we are saying; "this is normal, this is what to expect, this is how we do it". But we can't so easily do that with people in remote…
But I am going to say something, I am going to point out to my lovely colleague here Janet who does that kind of stuff in our unit. And I know she is talking to me all the time about; "I wish I could go out and look after people at home". We could extend our PCA service if we had a few more Janets and she could be potentially as part of team going places. We could clone a few Janets and have it flexibly available to support people.

Dr Chris Sanderson – Specialist Doctor Palliative Care: And it might only be three people a year.

Janet O'Brien - PCA for Palliative Care: Yes. So the challenge of getting them there, getting the equipment, having the equipment ready to go we need our little stash; it's walking frames, toilet seats and chairs, a hospital bed, some bush mattresses for some people.

CHAIR – Dr Tanzil RAHMAN: So Janet can I just focus on that for a second; there is a lot of talk about nurse practitioners; EN's, RN's a lot of people don't understand the scope of practice of PCA's which is actually potentially a lot broader than it could be. Noting also that PCA's are a lot easier to acquire from elsewhere in the health care system and deal with nurse registration, accreditations etc. etc.. So can you explain to us what you do as a PCA in that space?

Janet O'Brien - PCA for Palliative Care: It's endless really. Like we give a lot of care, a lot of support especially to families. We take care of hygiene, feeding as well because families they don't understand if someone is a choking risk how to feed them properly. It's endless.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Janet is our TLC expert, literally!

CHAIR – Dr Tanzil RAHMAN: Yes. It's an important part of a PCA. I think a lot of people just think they get juices the fact is it's a much broader role of a PCA.

Janet O'Brien - PCA for Palliative Care: It is very much

Dr Chris Sanderson – Specialist Doctor Palliative Care: I was going to say sometimes they direct the nurses as well and they might say; "look you need to come here first not go to that person", and give a good rationale as to why need to do that. And more often than not you will find the clinical staff will always listen to our PCA's in our unit because they are very in tune with what is going on with the, not just the patient but the family members.
And sometimes those people will say things to Janet and Raeleen that they might not necessarily say to us, so ladies then come and feed that back to us and then we feed it either to the doctors, to our management team.

Janet O'Brien - PCA for Palliative Care: We gain the trust!

Dr Chris Sanderson – Specialist Doctor Palliative Care: We do, we gain the trust and that can take days for us to actually get that trust.

Janet O'Brien - PCA for Palliative Care: The PCA's are also very good as assessment, changing ----------32:36 as it's deteriorating or improving or whatever.
So we rely on the PCA's; "That one is good today", "They are not feeding as well"… so we can change our process.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): There is also a practical problem with getting people home, so if we can get carers out there how are we going to accommodate them.

Dr Chris Sanderson – Specialist Doctor Palliative Care: There are lots of logistics.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): Yes. There are a lot of logistics around being able to do that; safe accommodation, being there overnight, all those things are dynamics of caring for these people and you are in a very volatile situation as well. So making sure that there are safety mechanisms there.

Dr Chris Sanderson – Specialist Doctor Palliative Care: So whether it's VAD or whether it is Palliative Care the people are receiving, when you are going to die in a remote place there are lots of challenges. Sometimes we manage to really help people and it works beautifully and sometimes it can't happen, it's a moon launch and we just can't get the window right and then sometimes people ask and want and it can't happen and some people choose to stay in town and that is the easiest part.

Anne Ryan (Unit Manager - Community Palliative Care Facility): It is quite heartbreaking when they can't go back, especially the elders can't go back to country and die it is actually difficult.

CHAIR – Dr Tanzil RAHMAN: We have heard a lot about that; so hence the question surrounding that.

But hypothetically let's say that we were providing more help and care and choice for people to finish up on country and lets say hypothetically we were able to procure more PCA's to help with that process of helping people out in remote locations, for example. What would be the limitations on what PCA's could do out there? For example what are the limitations on providing pain relief out there?

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility):
It depends on what their training is.

Janet O'Brien - PCA for Palliative Care: In Victoria, New South Wales and Queensland when I have done contracts there and from Victoria, we were actually to do medication rounds; obviously not as aides we could do that with an RN but we could do basic medication rounds and basic wound dressing too we were allowed to do, where here completely different.

Dr Chris Sanderson – Specialist Doctor Palliative Care: But we are used to making the medication plan work with the clinic, so we adjust and make it as simple as possible and we work with the clinic what they can do. So the clinic can manage the medication side of things normally.

CHAIR – Dr Tanzil RAHMAN: If there's a clinic.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Usually clinics, occasionally people are in an out-station or something where there is no one, that is quite challenging.
But usually we are working with a clinic and partnering up then we are supporting them, but what is not there is the real hands-on care the TLC stuff; turning them, the personal care, helping move someone, wash them, keep them clean and comfortable.

CHAIR – Dr Tanzil RAHMAN: So we know that it is very difficult to recruit and accredit for EN's RN's nurse practitioners; we do know they are mechanisms to be able to bring more PCA's into the system.

Anne Ryan (Unit Manager - Community Palliative Care Facility): We would love to. Am I speaking out of turn, we would love to.

Dr Chris Sanderson – Specialist Doctor Palliative Care: There's a casual pool, don't forget.

CHAIR – Dr Tanzil RAHMAN: Do you have a PCA shortfall here at the moment or are you maxed out?

Anne Ryan (Unit Manager - Community Palliative Care Facility): There is a casual pool they have started.

Janet O'Brien - PCA for Palliative Care: There is still a shortage.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I guess what we also talk about is flexibility to actually use them in our community team.
And there are some complexity around that but if we can make it happen it will be amazing.

Anne Ryan (Unit Manager - Community Palliative Care Facility): We would have to look at the actual VAD, the administration of the medications, the patients do they have to be able to do it themselves because you can't...

Janet O'Brien - PCA for Palliative Care: I can't.

CHAIR – Dr Tanzil RAHMAN: No, no. We are on that…

Anne Ryan (Unit Manager - Community Palliative Care Facility): But they can do the care if they decide it's going to be three days before they do it.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): Not every PCA is going to want to be involved with…

CHAIR – Dr Tanzil RAHMAN: No, no. We understand that too, yes.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): And there is going to be training to be a part of that.

BANTER

CHAIR – Dr Tanzil RAHMAN: No. The discussion here is more about how with our existing workforce or where we can bolster workforce to be able to support this process given what I just read from the Acting Chief Health Officer. Also given the concerns about partitioning people who are in the business of healing, people who are in the business of pain relief and potentially end of life pain relief and of a VAD service. So that is what I am thinking about.

And I want to just come back to one key point on that; protecting clinicians, you were talking about before. Again here when we are talking about essentially people withdrawing from treatment at the moment we know; are people able to elect to withdraw from treatment and are practitioners comfortable releasing people from withdrawing from treatment?

Dr Chris Sanderson – Specialist Doctor Palliative Care: You mean like dialysis or something?

CHAIR – Dr Tanzil RAHMAN: Potentially. All of this stuff we know that the only regular -------------- 39:33 interacts with this is the mental health act, in relation to sometimes that is used in and around; it can be separate, do you have any knowledge of whether or not those two things overlap at all?

Dr Chris Sanderson – Specialist Doctor Palliative Care: Sorry. I am not quite sure what you are asking, I think treatment stops for people all the time if it's not beneficial.

CHAIR – Dr Tanzil RAHMAN: Ok.

Anne Ryan (Unit Manager - Community Palliative Care Facility): So in this hospital we have many people coming to the end of the road with dialysis and that is process of decision making, consultation, talking to family, working out is it really that time because it doesn't go on forever. So that is something we are very familiar with in this hospital and we are involved in it a lot in the lead up and we can see if someone is probably in the last year of their life, they are getting frail, there might be a dialysis patient who has had a stroke or has got a new diagnosis of cancer. We go, this is all, it's a king hit coming to the end.

And then there is a process of decision making, communication, helping people understand what is happening, that the end is coming and then how that actually happens that we stop dialysis. That is probably the most common thing here but it might be patients having chemotherapy were stopping that. It might be people who are very, very sick, septic or whatever they have had a lot of antibiotics and they are still dying, basically.
So do we start to de-escalate all that treatment which is very traumatic for people and not helping them and give them different options. Because while we are doing all those things they can't get out of hospital.

So that is a process we are really, really familiar with here in the hospital and we get involved with those patients, but they are almost always referred to us and we are part of that.

Anne Ryan (Unit Manager - Community Palliative Care Facility): And I think when it comes to VAD and those type of patients they are being treated for so long with the renal patients that are living, living, living and then sorry, we are stopping now and then they may have a week or days to weeks left. So VAD, they are not thinking about all this during the process, they are thinking treatment, treatment, dialysis every three days. So the difference is … different trajectories.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Is that what you were asking from me before?

Matthew KERLE: Yeah, it's ok I was just trying to get ------------- 39:38

Dr Chris Sanderson – Specialist Doctor Palliative Care: So that's an important part of our clinical work all the time.

Matthew KERLE: What we want to understand, what we have heard a lot from Indigenous people who live on communities is about; withdrawing from treatment rather than positively engaging with VAD. So we want to really understand from a health care point of view; so when you're looking at someone, say; in stage renal failure or in stage cancer…

Dr Chris Sanderson – Specialist Doctor Palliative Care: They don't need VAD, if they stop dialysis they have got two weeks to live.

CHAIR – Dr Tanzil RAHMAN: Well this is the key point.

Matthew KERLE: So this is the question I want to ask.

Oly CARLSON: So what is happening is, we are probably going to redefine the words 'voluntary assisted' in the Northern Territory.

CHAIR – Dr Tanzil RAHMAN: To think in a broader context right; so we should just be clear this is all a work in progress but what we are starting to understand is the word 'voluntary' and the word 'assistance'… go back to the word 'euthanasia' "to die a good death"; people also understand that 'assistance' might be construed in a more broad term and so if people withdraw from treatment, at what stage can they withdraw from treatment? Are there limitations? Are they issues for clinicians in terms of allowing them to discharge themselves?

Dr Chris Sanderson – Specialist Doctor Palliative Care: Ok. So now I understand what you were asking.

So people can withdraw from treatment at any point. No one can be forced to have dialysis who doesn't want to have it. No one can be forced to have cancer treatment who doesn't want it, unless as you said there is a mental health concern about the quality of their decision making?

Matthew KERLE: That's right, yes.

Dr Chris Sanderson – Specialist Doctor Palliative Care: But the decision is still made on a clinical basis of whether it is beneficial or non-beneficial.

Matthew KERLE: Yes.

Dr Chris Sanderson – Specialist Doctor Palliative Care: We don’t give people futile treatment.

Matthew KERLE: No. Of course.

Dr Chris Sanderson – Specialist Doctor Palliative Care: You know, that is just going to be burdensome and make them feel terrible; it prolongs their life but they are having a horrific time and they can never escape from hospital.

So that sort of thinking is going on all the time behind the scenes and it is very rare that it’s a mental health reason that we force people to have treatment. And there is no obligation, people make their own decisions about what they want and what they don’t want all the time.

So a lot of people say; “I don’t want chemotherapy”, I don’t want to spend my last days hooked up to chemo agents”.

Matthew KERLE: Yes.

Dr Chris Sanderson – Specialist Doctor Palliative Care: There is a whole bunch of people who say; “I don’t want dialysis I know my kidneys are failing I don’t want to live on the machine”. They know exactly what that mean because they see it all the time.
So there is no… that is not a problem, that is not an issue, if that makes sense. That is not euthanasia either, that is choice. That is choice!

Matthew KERLE: Correct. And is that choice, that has sort of been coming through and looking at a broader view of finishing well, rather than a positive act of taking a substance which ends your life than a negative act of withdrawing from treatment so that you finish up, maybe pain medication.
So what does it look like when say; as a clinician and you look at someone’s condition and what they are suffering from… and clinically the prognosis is likely that their quality of life is very, very bad and will worsen in a short period of time, what are the discussions like when you talk to the person; if they may not be aware of the option?

Dr Chris Sanderson – Specialist Doctor Palliative Care: So those conversations are our bread and butter. So getting people up to speed so that we are all understanding what is possible; we have to understand from their point of view what quality of life means.
People may be going through what looks to us like hell but they are hanging out for a wedding or a grandchild or just hanging out because that’s what they want to do. That is a conversation and they’re the conversations we have all the time with people.

We can say; “We are not going to send you to ICU again, because putting a tube in you now means you will die on that machine and your family are going to have to be in place to say; “turn it off”.” “So we are not even going to offer that to you now, that is where you are up to”.

And then we will support people to get their heads around what that means for them.

So we are talking prognosis and burden, some lesser treatment and quality of lifestyle for people all the time and helping them in their own way and in their own terms to get their head around that, so then they can make a decision based on some reality.

And some people choose still to say; “I want more chemo” or whatever…

Matthew KERLE: In a few of the communities we heard people say their loved ones had been treated in town, in a hospital a long way away and then they decide they want to come back to community and finish up, but they either die in the hospital or they die in a plane on the way and they don’t even make it.

Dr Chris Sanderson – Specialist Doctor Palliative Care: We leave it too late sometimes.

Matthew KERLE: Yes. And it is probably around; what we have heard in communities is that it is very, very important to people culturally to finish; like a good ending. So we say, what does it look like to finish up well? What does that look like? And they say…

Dr Chris Sanderson – Specialist Doctor Palliative Care: You've been doing our job for us, thank you (laughter)

Matthew KERLE: … on my country, in community surrounded by all my family and with pain relief. Then everyone can come and say goodbye and because it takes time for people to get there. It might take days, a week, or an extended period of time and then they pass away and then there is a whole lot of cultural things that have to happen there then there is cultural decision making occurs.
Probably one of the things that has come out is having those discussions in time; and obviously there is infrastructure, aged care and community and planning. But in time so that that decision can be meaningfully made.

Dr Chris Sanderson – Specialist Doctor Palliative Care: That is really interesting if that's what you're hearing, because I think all of the time I am here in the hospital and my doctors are here in the hospital advocating for; "don't leave it too late" this person is going to run out of time, they are going to miss their chance to go home.

I think the hospital by default keeps treating people and probably too long sometimes; but this is a culture change, something about the way medicine works and the way we think.
And we have got doctors come in "Yay" and we'll give it another go…

… and I'm the person that walks in the room and goes; "stop, stop, stop, stop, stop, stop everything".
(laughter)
We need a family meeting now!

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): Have a family meeting, discuss with the…

Dr Chris Sanderson – Specialist Doctor Palliative Care: Change direction now otherwise this person is going to be stuck here and they will die, where else are they going to go now? So that's why it is my who comes in; me and my team and people I am training. We are the ones who go and say; "Look seriously, it's time to change direction".
So that is a big story about modern medicine, really. It really effects people when they are remote, in town your family might be the next suburb away, but here they can be 1000kms away.

CHAIR – Dr Tanzil RAHMAN: Anne. Did you want to chip in on that, just a couple of things?

Anne Ryan (Unit Manager - Community Palliative Care Facility): No. Chris does it very well, she does have the conversations very well.

I think for that to happen we really do need a team of people who can actually make that happen right away. Go out to the communities, have things to help the families; like you said PCA's and that I think a team to just go and say; "Ok this one is going out to community today".

Sometimes the families are happy to look after them, do all the…

Dr Chris Sanderson – Specialist Doctor Palliative Care: And sometimes we need to teach them.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Yes. We need to teach them these cultural issues…

Matthew KERLE: And then that's after the decision has been made; sorry that is after the decision has been made to go back into community.

Dr Chris Sanderson – Specialist Doctor Palliative Care: People need to understand that person is going home to pass away. Everyone has to be on the same page otherwise it is going to be major…

Matthew KERLE: And before there is cultural decision making and those decision makers might be out on community 10 hours away…

Dr Chris Sanderson – Specialist Doctor Palliative Care: Yes. So as long as they come in for a meeting, you have got to get everyone back in. So there is lots of stuff.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): It's also complex because of the timing and sustainability of it. I mean the renal ones; people are on dialysis they are not making urine we know they are going to die within about seven to 10 days, and
that's a manageable timeframe for the community, for the families, for the clinic to actually sustain that. Because the problem with end of life care it doesn't happen between 8:00am – 4:30pm, you have got nurses who have been called out at 2:00am because the family are freaking out over something. Those nurses then need rest relief, so they can't front up to work until… so there is an impact on the whole community to keep somebody out there.
And sometimes the families just can't do it.

Matthew KERLE: So what is a good time; say if you wanted to say "alright this person has seven to 10 days", to get them back out to community… assuming that the basic infrastructure is there, what sort of time frame is the likely end of life, seven to 10 days or a little bit more?

BANTER

Dr Chris Sanderson – Specialist Doctor Palliative Care: We could do a guestimate, usually, but we have had people who have gone and we are thinking; "Oh they have got a few weeks to go" and then two days later they pass away.

Anne Ryan (Unit Manager - Community Palliative Care Facility): A lot of the Aboriginal too, that we have witnessed is very much spiritual, quite often they just…

Oly CARLSON: They know when they're ready.

Anne Ryan (Unit Manager - Community Palliative Care Facility): It's almost like they just say; and we have had that old man recently, absolutely beautiful he got back out to country he wanted to go, was desperate to go out to country. He said; "All my family are coming they told me they are ready for me to come", and he went out to country and he died in less than a week. Whereas I would have thought he would actually last a lot longer.

Matthew KERLE: So while we are on that, giving a prognosis. How difficult is it medically, even if you are saying six to 12 months to make a prognosis of; "Ok this is roughly how long you have left". How difficult is it to put a number on someone, saying; "Ok this is how long you have got based on your condition".

Dr Chris Sanderson – Specialist Doctor Palliative Care: The numbers part; like getting it accurate commonsense of like, it's weeks it's months it's this many months is hard.
But I think the skill we get is knowing; you know I think we can say that someone is in the last year of their life, we can see they're coming into hospital more often, they are getting sicker, they are not walking around, they are not the strongest, we treat them and the treatments aren't working anymore. We would then say; they are probably in the last year of their life, so I think in kind of blocks like that.

Matthew KERLE: So would you say it is less about a specific 12 months versus Ok this person is; they are on a trajectory and they are not going to come back out of that.

Dr Chris Sanderson – Specialist Doctor Palliative Care: In clinical practice it is, yes. But I understand for legislation purposes you need to set something up; and I think the year that was in the report was probably a reasonable.

CHAIR – Dr Tanzil RAHMAN: The ACT has chosen not to is the point. So the ACT is the newest jurisdiction that doesn't have a 12 month restriction.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Yes. I don't like that myself.

CHAIR – Dr Tanzil RAHMAN: And why is that?

Dr Chris Sanderson – Specialist Doctor Palliative Care: I have been watching what is happening in Canada where they have sort of got a process that is not anchored in a prognosis; and I think that opens the door to actually euthanasia for people on the basis of disability and I am not sure if we are ready for that in Australia. Ethically I am not ready for it. It may well be where our society ends up, but to me it is huge change, it's a huge thing. I would like to know that if we are talking about administering something to end someone's life; it is for someone who is already in that process of that road.

CHAIR – Dr Tanzil RAHMAN: End stage. Yes.

So you're obviously intimately familiar with the model that is proposed in here. I just want to ask from the rest of you; are you all familiar with this model or is it worth me just quickly talking it through to see if you have any… because I would like to ask about that, just briefly.

In broad brushstrokes; see a medical practitioner first time, if they agree that you have got 12 months or less and that you have got capability to give consent, etc,. Waiting period which isn't actually specified in this report but is generally a couple of weeks everywhere; five days or nine days then you have to see a second doctor, again the second doctor the standard varies for whether they need to be some specialist in that particular prognosis, or whether they can be another GP etc. If you get two people to sign off you get to a third stage of written consent a couple of witnesses and then you get to an administration team, which again varies from place to place…

Dr Chris Sanderson – Specialist Doctor Palliative Care: What sort of administration?

CHAIR – Dr Tanzil RAHMAN: Yes, that's right! Then you get to a medical team, if you like, which could be a nurse practitioner could be a doctor depending on where you are it changes to actually help with administrating a substance to help you pass on.

So that is the broad brushstrokes of the set-up and separate to that review boards and government structures which are separately identified.

Does any of that to you, as practitioners raise any red flags or does that sound broadly right or is that overly bureaucratic; any shoot from the hip thoughts about that?

Anne Ryan (Unit Manager - Community Palliative Care Facility): Yes. I am just concerned trying to find a practitioner in the joint.

CHAIR – Dr Tanzil RAHMAN: That would go for it, yes. And so in that regard that is why we are thinking about all the 1400 practitioners that we have and we know how many people access public primary health care versus private primary health care, and we know that if there is an accreditation system to be able to allow people to opt in or opt out, we might have a better chance of providers, notwithstanding that private practitioners; for example in Alice Springs are thin on the ground and diminishing, as you say.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Could they use doctors up in Darwin and things like that as part of the team?

CHAIR – Dr Tanzil RAHMAN: Yes, they could. So not only telehealth…

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): No sorry, digital. I was just…

CHAIR – Dr Tanzil RAHMAN: Yes, there is the telehealth we kind of all know…

Dr Chris Sanderson – Specialist Doctor Palliative Care: There is the temptation to think about telehealth as maybe solving some problems.

CHAIR – Dr Tanzil RAHMAN: Yes.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I get that; both for the resources and travel and accessibility, blah, blah, blah.

But I have to say; speaking as someone who tries to do family meetings on telehealth sometimes, it is incredibly hard to read the word and really have a sense of what is going on. Whether there is anything else going on beneath the surface.

Matthew KERLE: It could be as simple as people's eyes opening, or facial expressions.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Hand signalling and there are a lot of non verbal communication that goes on in any of these discussions.

CHAIR – Dr Tanzil RAHMAN: Dr. Sanderson that is very consistent with what we have heard whether you are talking about court proceeding, primary healthcare, whether you are talking about palliative care; we are not sure that telehealth is robust enough to cope with all of this at the moment.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): Yes, it is. We have all dealt with it in the clinics.

Anne Ryan (Unit Manager - Community Palliative Care Facility): It's hard.

CHAIR – Dr Tanzil RAHMAN: And then there is a layer as well with interpreters, right? Whether or not people when they are on those are able to actually…

Anne Ryan (Unit Manager - Community Palliative Care Facility): Yes, what they are hearing…

CHAIR – Dr Tanzil RAHMAN: fully be across what they are hearing and understanding.

Now we have about 15 minutes left; I want to ask you about pain relief as practitioners and palliative care people.

Again I just want to reiterate, anything you want redacted from any of these proceedings or anything you don't want to say, I don't want anyone to say anything that is going to perjure them or make themselves uncomfortable.

Matthew KERLE: Should we offer to go in-camera for this part?

CHAIR – Dr Tanzil RAHMAN: No, no. We don't have to do that in the first instance, let's just have a discussion and then if anyone wants to say anything, they can say whatever they want to say.

Just by way of anecdotal background, if you like; two years before The Rights of the Terminally Ill Act; I grew up in Darwin I did a school project about voluntary euthanasia, and I can remember in 1993 being in the ICU at RDH talking to an ICU medic who blew my mind by explaining that sometimes when people are so sick and suffering so much we give them pain relief and then we give them more pain relief to help them pass on.
It was mind blowing as a 15-year old to learn that.

Now we haven't known about whether or not those kinds of things happen in community settings or whether or not they happen on the ground. And we have been surprised to learn in collecting testimony, that people have freely volunteered some instances of stories in that regard saying; "my father/mother as it were was in a great deal of pain and then we all decided as a community in consultation with the medical team that we did not want them to suffer anymore".

Now, I don’t want anyone as I said; to say anything that will perjure themselves, but generally speaking has anybody able to speak to whether or not those practices; which we know to be not uncommon in urban settings…

Anne Ryan (Unit Manager - Community Palliative Care Facility): Yes. I did community for a little while. I had an incident; it didn’t involve me giving medications or anything. We had a woman who was on quite high doses or oral opioids and that, she actually wanted VAD but couldn’t do it.
And at that time the doctor and I had to talk to her daughter and say there’s large amounts of opioids in the house; if we come one day and she has passed away and that has all disappeared, sorry you have to go to… it’s like a process we have to declare it to court and all that.

CHAIR – Dr Tanzil RAHMAN: Of course.

Anne Ryan (Unit Manager - Community Palliative Care Facility): So that was the only incident I have really had. It was quite disturbing… it made us think at the time, if we just turn a blind eye…

CHAIR – Dr Tanzil RAHMAN: Yes.

Anne Ryan (Unit Manager - Community Palliative Care Facility): If she wanted to do, she didn’t. She didn’t do anything like that, she passed away. But it was like; ‘do we turn a blind eye’… ‘whether it happens, the family are doing it, she has made that decision’. But because VAD wasn’t there we had to give them all the legals; “if you do this, you will still have to be reported”.

CHAIR – Dr Tanzil RAHMAN: Yes.

Anne Ryan (Unit Manager - Community Palliative Care Facility): So, it could happen quite easily.

Dr Chris Sanderson – Specialist Doctor Palliative Care: It could and it may be there is some stuff that is just not visible on the surface. But in my practice; I look and see within a hospital what people are actually being prescribed and are being given, because it is all recorded!

I don’t see that as a common practice at all, like really not at all. I am aware in my whole career of 25 years of maybe one or two clinicians in some situations who have practiced unofficial euthanasia. I aware of one in Sydney that…

But I think there are some people who just have poor practice, but they are just not very good at using opioids; and that is misunderstood by them and by family what the intention of their prescribing is.

CHAIR – Dr Tanzil RAHMAN: Yes.

Dr Chris Sanderson – Specialist Doctor Palliative Care: When we prescribe, when anyone I have taught prescribes it’s like; you need to be able and stand up in a Coroner’s Court and justify the dose you gave as medicine is proportionate to their symptoms.

If a person dies whilst they’re having pain relief, whilst they’re on an infusion with an opioid in it, that’s Ok they are a dying person, you’re allowed to die of that. Our job is to manage the pain relief and to do it proportionately.

So we create and worsen a lot of people’s fear around opioids sometimes; these conversations I think it’s often really, really misunderstood including by doctors and nurses.

So it’s what is a really hard space to work in. It is a really complicated space to work in.
But when I really think about what I see in terms of what people prescribe here, I am not aware, I am not aware of people intentionally shortening people’s lives.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): You are actually…

Dr Chris Sanderson – Specialist Doctor Palliative Care: In the other way it is kind of like; “please give them a bit more”, seriously don’t be worried about this now.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): …nurses are scared to give it because, particularly around morphine but morphine hastens death, morphine becomes addictive, you don't need morphine until you are really, really, really in a lot of pain. So it actually, it's the other side. People are too scared to actually give it.

CHAIR – Dr Tanzil RAHMAN: Yes. We have heard morphine come up a lot.

Anne Ryan (Unit Manager - Community Palliative Care Facility): It scares families.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): It scares families morphine. We have had nurses given the last dose and the patient has died an hour later or 20 minutes later; what have you done, what have you given him…

Anne Ryan (Unit Manager - Community Palliative Care Facility): And then we have got the patients family; "No morphine".

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): We are not allowed to give them pain medication.

Dr Chris Sanderson – Specialist Doctor Palliative Care: So these are conversations; we engage with this stuff all the time.

CHAIR – Dr Tanzil RAHMAN: Yes. So for us it has been interesting on the other side where it is; "Don't want that needle to hasten death, but fine with morphine to hasten pain relief". So that has been a surprise to us to hear that at all on community, people have brought that up. So again, from the clinician side it is really useful for us to know what the experience is within a hospital context and then out bush, we know that there are controls of course as well. But just trying to understand the reality of the situation on the ground is very important for us.
What does pain relief look like for people out, when they are out in country.

Dr Chris Sanderson – Specialist Doctor Palliative Care: We use a lot of patches.

CHAIR – Dr Tanzil RAHMAN: Yes.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I would say actually nursing homes are almost as hard to get good pain relief in, as people remote because they can't have… our ideal is; if we could have a break through an extra dose when they need it for extra pain.

CHAIR – Dr Tanzil RAHMAN: Yes.

Dr Chris Sanderson – Specialist Doctor Palliative Care: That's what hard to manage in a remote setting where there not someone around who can help.
And maybe the family aren't quite confident or competent to manage the difficult medication.

So at home we teach people and train people and often they will end up doing a wonderful job of giving those extra doses of medication when needed.

So when you can't get an extra dose for extra pain we tend to use a background, so long acting to try and cover. It's not always as good, but generally speaking we can do that.
So it's either patches; and we do have those pumps/infusions in many communities the clinic have got those now and we can help them with that for the final stages.

CHAIR – Dr Tanzil RAHMAN: And in dialysis situations…

Dr Chris Sanderson – Specialist Doctor Palliative Care: Do you agree with that, guys.

CHAIR – Dr Tanzil RAHMAN: Yes? For -----------1:02:18 dialysis setups, are people able to look after themselves, if they go out bush to finish up? We have heard in the past, long past, in some places they were able to… but is that something that has happened any time recently?

Dr Chris Sanderson – Specialist Doctor Palliative Care: Able to look after themselves in what way?

CHAIR – Dr Tanzil RAHMAN: Yes essentially; self administer and…

Matthew KERLE: Self dialysed.

CHAIR – Dr Tanzil RAHMAN: Yes. Self dialysed.

Matthew KERLE: That's with a chair set up…

Dr Chris Sanderson – Specialist Doctor Palliative Care: There is a few dialysis. There is no much self dialysis I don't think happening around Central Australia now.

Anne Ryan (Unit Manager - Community Palliative Care Facility): No, no, no. It's very limited here.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): I think there's the ----------------------------1:02:51 talking to -----------------------1:02:53 yesterday. We need one in town.

Anne Ryan (Unit Manager - Community Palliative Care Facility): But you mean as in administering opioids -----------1:03:00 higher

CHAIR – Dr Tanzil RAHMAN: It could be either or. No actually I am talking about opioid specifically now; actually just talking about dialysis, the ordinary run of the mill stuff.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): You'd probably need to talk to the renal team.

CHAIR – Dr Tanzil RAHMAN: Yes. I know, I am aware.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Yes. The renal doctors can answer that question.

I mean there are some patients who can self-dialyse and there are some places in which that can happen. But I am not sure how common it is, I don't think it is that common.

CHAIR – Dr Tanzil RAHMAN: By the sounds of it, it's pretty uncommon but people brought up to us that in the long past they were able to do that.
So we were just trying to work out if that capacity has diminished over time.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I think maybe, it has.

Anne Ryan (Unit Manager - Community Palliative Care Facility): I think it's due to the lack of staff as well and a lot of the communities, they can't regularly be there. I know some of the communities do it but, they have got dialysis…

Dr Chris Sanderson – Specialist Doctor Palliative Care: I have certainly had one patient who had been self-dialysing in Ti Tree was it?

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): Yes.

Dr Chris Sanderson – Specialist Doctor Palliative Care: For many, many, many years before he got sick.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): Purple House has moved in to a lot of that space as well.

Matthew KERLE: I have just got some really quick questions that I took notes from earlier. Anne you said two nurses for; what was the number of square kilometres?

Anne Ryan (Unit Manager - Community Palliative Care Facility): 1.6 or 1.3 million

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): South of Elliott.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Tennant Creek.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): The other issue is we also cover the APY Lands (Anangu Pitjantjatjara Yankunytjatjara) of South Australia.

Matthew KERLE: Ok.

Dr Chris Sanderson – Specialist Doctor Palliative Care: We sneak across to WA a bit too.

Matthew KERLE: So is that communities that don't have a clinic?

Anne Ryan (Unit Manager - Community Palliative Care Facility): No, no. They have got clinics but it is more support for the clinics the palliative care.

Matthew KERLE: Oh! It's the palliative care nurses.

Dr Chris Sanderson – Specialist Doctor Palliative Care: So I get retrieved to Alice Springs Hospital; we review them and support them.

Matthew KERLE: Ok.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): So if we get a request from somebody from South Australia for this…

Matthew KERLE: So that is roughly from Elliott through to the APY Lands?

Dr Chris Sanderson – Specialist Doctor Palliative Care: Yes.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): Because that's a tri-state area.

CHAIR – Dr Tanzil RAHMAN: Well at the moment we cannot cross borders across any of these services, is pretty much the state of how the different laws are set up. So that conversation has barely even been broached.

Matthew KERLE: Tri-state, cross border, blah blah blah… there (laughter)

So just a quick on; so in your submission you talked about recommending that they be fellows. So the two medical people have to sign off…

Dr Chris Sanderson – Specialist Doctor Palliative Care: They need to be able to practice independently so I guess a registrar is still being supervised.

Matthew KERLE: Ok. I am just trying to understand… like I don't know much about the levels of doctors. So we heard evidence from the AMA that they recommended that at least one of them be a specialist in their college.

CHAIR – Dr Tanzil RAHMAN: Yes. Essentially, yes. I mean this is about the standard of the core medical practitioner and the consultant practitioner. I am not talking about administration but we just want to make sure what is the appropriate level of checks and balances for decision making on prognosis.

Dr Chris Sanderson – Specialist Doctor Palliative Care: If you think about it in numbers, the doctor needs one practice independently, not without supervision. So for a GP that means they have got the GP qualification or GP registrar, the same in the hospital.
Because everyone below that is still training.

Matthew KERLE: Ok. So if someone is not for example, a nephrology specialist or a cancer…

Dr Chris Sanderson – Specialist Doctor Palliative Care: You are technically a specialist, yes.

CHAIR – Dr Tanzil RAHMAN: The fellow of the Royal College…

Dr Chris Sanderson – Specialist Doctor Palliative Care: You have completed your training you are not being supervised anymore.

CHAIR – Dr Tanzil RAHMAN: An unsupervised medical practitioner, essentially is what…

Matthew KERLE: So that would be the equivalent of the specialist that…

CHAIR – Dr Tanzil RAHMAN: Well it varies but basically, yes.

Matthew KERLE: Alright, tick.

Dr Chris Sanderson – Specialist Doctor Palliative Care: A specialist or a generalist or a generalist specialist.

Someone who can practice without supervision. That is really the reason for setting it at that level, I think.

Matthew KERLE: So Fred, you talked before about; there is a question about how… I wrote down a question; "How to refer people in palliative care to VAD because we want to have that separation". So do you have any suggestions on, if there is someone in palliative care and it is appropriate, say for example if the discussion comes up what would the referral to VAD look like so that it is sufficiently separate from palliative care.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): I think it is probably like any specialty you need to do a formal referral and that would come probably from our team. It would be sort of like...

Dr Chris Sanderson – Specialist Doctor Palliative Care: We would be happy to make those referrals.

Anne Ryan (Unit Manager - Community Palliative Care Facility): And we would be able to have information to give, to make sure that they have got all the information.

Dr Chris Sanderson – Specialist Doctor Palliative Care: And we could also just give people the information we have self referred.

Matthew KERLE: So as in, you might know someone who usually handles that kind of thing and you could write a referral to that doctor, or to…
Anne Ryan (Unit Manager - Community Palliative Care Facility): That's if there is one here.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I think the service should be well enough identified that there is a portal through which you can refer. And I think people should be able to self-refer is the other thing.
I don't think they should have to grovel around and try to find someone who will refer them, I don't think there should be secret squirrel business, I think it needs to be really transparent.

Matthew KERLE: Unless they had an online portal.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Because I think the way it started in Victoria was kind of like; "Well we don't know who is going to do it and who isn't going to do and we are not going to tell you. You have to find out yourself and that is why you have navigators". And it was really like hard, I think for people.

CHAIR – Dr Tanzil RAHMAN: It was. Victoria and South Australia had the fastest but also the most cumbersome processes initially.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Yes.

CHAIR – Dr Tanzil RAHMAN: The only place where the numbers are doing this, is in Queensland and in other places…

Dr Chris Sanderson – Specialist Doctor Palliative Care: Is it a good thing?

CHAIR – Dr Tanzil RAHMAN: I am not passing a judgement about it but in terms of the regulatory model and the legislative framework to support it, that the numbers they're out. We are not picking and choosing from them anyway, the ACT is the only place that doesn't have an operational model yet it has just got a law passed but no actual VAD has been implemented yet. From the end of this year will be the first time people in the ACT can access it. But ACT does deviate on the 12 month prognosis standard, which is one of the more interesting developments. And as you know from The Rights of the Terminally Ill, was a lot more permissive in allowing how things should be. So we face a lot of questions about; "Why can't you just scrub out 1995 and put in 2025" and then Bob's your uncle.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): 22 steps.
22 steps back in 1996.
Just coming back to that model you were talking about.

CHAIR – Dr Tanzil RAHMAN: Yes.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): One of the issues and it was something from 1996 ---1:09:10 where is the family in all this? What is the process of having, not necessarily the family involved because sometimes family won't give permission, but how do we acknowledge that a family is going to be affected by this.
And a lot of the time, a huge amount of time they will be supportive of it.

CHAIR – Dr Tanzil RAHMAN: Yes.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): But there are going to be times when it is done very secretly and I think Chris, you talked about a Western Australian incident in the Kimberley where there was a request by an Aboriginal person but it had to be done…

Dr Chris Sanderson – Specialist Doctor Palliative Care: Somewhere else. I want to be somewhere else I don't want family to know I am doing it off my own back.
So it is a lot of complexity.

CHAIR – Dr Tanzil RAHMAN: Well this report is worded around individuals having choice without thinking about group decision making, cultural decision making, families and consultation as broadly.
Chapter, appendix 9 of this talks about; "things should be done in a culturally sensitive and appropriate manner"; but doesn't a whole lot more detail.

Dr Chris Sanderson – Specialist Doctor Palliative Care: There is no respect for that I think. I mean I think that has got to be an ongoing process to work out what that actually means.

CHAIR – Dr Tanzil RAHMAN: And part of what we are doing is trying to understand what that might…

Dr Chris Sanderson – Specialist Doctor Palliative Care: You've done a lot! That's really…

CHAIR – Dr Tanzil RAHMAN: Well we are doing the best we can. (laughter)

Dr Chris Sanderson – Specialist Doctor Palliative Care: Can I actually point out one thing else? We don't have a bereavement service here, we do not have a bereavement service for our existing clients. We did but when the unit got set up, the position kind of went away and I think that is something I could identify as a resource that is going to be needed across the board for our community. Not just for palliative care and VAD patients but also deaths, traumatic deaths people who have had terrible things happen and they have died in the hospital somewhere. There is a lot and dying in this community and not enough bereavement services.

CHAIR – Dr Tanzil RAHMAN: That is a very interesting…

Oly CARLSON: Does it have a chaplaincy…

Dr Chris Sanderson – Specialist Doctor Palliative Care: We have got a fabulous chaplain we have got a chaplaincy service, that is not quite the same thing. We do use them though.

Anne Ryan (Unit Manager - Community Palliative Care Facility): It's more social though.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): It's more social though? … If I learn someone passes immediately you have got family you have supported. It's when the weeks would go on when everyone has gone back to doing their things, you're left.

Dr Chris Sanderson – Specialist Doctor Palliative Care: We had one young woman die in the unit and I know this one's family and the mother told me six months later; her sisters have all been drinking since and both of her brothers have been in jail ever since, they have all lost it! They were so distressed and it's a bereavement response.
So we haven't got the capacity to put support in for people…

CHAIR – Dr Tanzil RAHMAN: So I'm mindful that it's 11:30am and I don't want to keep you guys too far beyond that, we have got…

Dr Chris Sanderson – Specialist Doctor Palliative Care: But I have flagged that as something that should be considered as a need also…

CHAIR – Dr Tanzil RAHMAN: That is extremely important for us to know.

Dr Chris Sanderson – Specialist Doctor Palliative Care:… in the VAD context but broader.

CHAIR – Dr Tanzil RAHMAN: So in the same spirit Dr Sanderson; one of the things that is clear across the country is whenever a VAD gets passed the demand on palliative care goes through the roof as well elsewhere.
What extra would you need or could you cope with if the law got passed in this space?

BANTER

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): There is a template there with a lot of suggestions.

CHAIR – Dr Tanzil RAHMAN: We have seen that but also trying to get it on the record for hearing purposes as well.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I think more bereavement services, I think to develop our return to country capacity so whatever that looks like; so really flexible resources that we can support.

We use [acronym] 1:12:37 so our retrievals tend to fly people home which is fantastic and quick when it happens but, it is not very flexible. Often you have got 20 people who have come here for a family meeting, they also need to get home we need to get equipment home.

So I think we have thought a lot about whether we need a vehicle, some kind of vehicle or sharing a vehicle with Purple House or something. But a road base way to get people home.

CHAIR – Dr Tanzil RAHMAN: That is interesting because in that space we are talking about essentially, social workers, PCAs, logistics and infrastructure support but not necessarily more doctors and nurses in order to provide more palliative care.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I think actually nurse practitioners or more community nurses but maybe based in places like Tennant Creek and Gove so we can actually have some more. We are very intensely based in town at the moment but if we had an MP in Tennant Creek they would be seeing and providing hands on care for people there and could help people in all the communities around Tennant Creek, that would be part of the palliative care network.
CHAIR – Dr Tanzil RAHMAN: Yes.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): They need a 4-wheel-drive bus where the carers can sleep and deal with the patient.

Anne Ryan (Unit Manager - Community Palliative Care Facility): Take equipment out.

Sharon Clarke (Clinical Nurse Coordinator - Community Palliative Care Facility): Take equipment out have it all there set up to go and look after them for two or three days…

BANTER

Janet O’Brien - PCA for Palliative Care: Hey! I’ve got a really good one as an example. The big bus with the 4-wheel-drive suspension, amazing.

CHAIR – Dr Tanzil RAHMAN: When we have a chat with -----------1:14:10 later today, so maybe we will talk about the bus.

Anne Ryan (Unit Manager - Community Palliative Care Facility): There are lots of logistics for it.

Janet O’Brien - PCA for Palliative Care: Look, the list is endless.

Dr Chris Sanderson – Specialist Doctor Palliative Care: But you are absolutely right. I think this is all about quality of death and dying and choices in this town and there has got to be not just one choice. Not just a choice for VAD.

CHAIR – Dr Tanzil RAHMAN: Well a choice and help to finish up well.

Dr Chris Sanderson – Specialist Doctor Palliative Care: Yes. I really like that way of framing it actually.

CHAIR – Dr Tanzil RAHMAN: Yes, well that is starting to resonate so we are trying to think broadly about that.

Matthew KERLE: I might be the sub-heading of our report.

Fred Meegle (Clinical Nurse Specialist - Community Palliative Care): Don't use euthanasia, that still has connotations.

CHAIR – Dr Tanzil RAHMAN: Yes, what we find is that there is a lot of sentimental attachment to The Rights of The Terminally Ill terminology still and that phrase, as we pointed out; "how the choice to finish up" is resonating well, particularly outside of urban centres.

But what we are really trying to do is make sure that in principle, good will and support behind the 2024 report has some actual legs to it. So that we don't just pass the law, make a promise to Territorians to be able to do something and then find that we have such capacity deficits or lack of implementation plan behind this, that it can never really get off the ground easily.

Look, you guys have been fantastically helpful today we really appreciate all the time you have offered us.

We still have a window of written submission time that is available until the end of next week; any of you as individuals as well if you want to write in or even if you want to phone in, we have a hotline as well where you can just give verbal testimony if you want to say anything beyond what you have said today we will record that all as well; with all the same protocols of privilege and confidentiality are part of those as well.

We will be doing our best in earnest as I said, to report back to the Legislative Assembly by September and then we will see where the process goes from there.

But this will be an ongoing conversation I imagine.

Dr Chris Sanderson – Specialist Doctor Palliative Care: We are really keen to continue to be part of it constructively.

CHAIR – Dr Tanzil RAHMAN: Yes, fantastic. We really appreciate that as well.

Dr Chris Sanderson – Specialist Doctor Palliative Care: I think we can help you make it work well and avoid some of the pitfalls.

CHAIR – Dr Tanzil RAHMAN: Absolutely. It is not going to happen just by passing a law, saying it is now…

Matthew KERLE: Decriminalised.

CHAIR – Dr Tanzil RAHMAN: Decriminalised. That is not really enough.

Dr Chris Sanderson – Specialist Doctor Palliative Care: That is what scares me (laughter)

CHAIR – Dr Tanzil RAHMAN: I don't think, no. I mean certainly we can give you the undertaking as a committee that we are thinking about the broader landscape and we will try and get substantial reports to reflect all of these concerns and considerations.
Then it is really in the hands of government after that and we will see what happens.
So touch wood we move the agenda forward for Territorians.