

Navigating Voluntary Assisted Dying

How to get the help you need

Speakers

Susan Jury (head of the VAD Car Navigator Service Victoria)
Alice Morison (head of the VAD Car Navigator Service WA)
Gareth Wahl (emergency physician and VAD practitioner, WA)
Steve Offner (Go Gentle Australia)

Steve Offner

Okay, so people are slowly joining the webinar. If you're there listening in or watching in, feel free to type something in the chat just to let us know that you can hear.

It looks like we're live and we're going. All right. I don't know how many more people are going to join us. But we will get started I think.

Anyway, welcome everyone. We'll get things going. Welcome to this Go Gentle Australia Dying to Know Day webinar. My name is Steve Offner, as you can see. I'm Go Gentle Australia's communications director. And I'll be here doing some of the tech and asking some of the questions for the panelists as we go.

It looks like it's a great turnout. We've got several hundred people attending so far. And thank you, everyone for setting aside time on your Thursday evening to hear more about what is an important topic of voluntary assisted dying.

So, before we get going properly, some housekeeping. This is a webinar. It's not a Zoom meeting. So everyone's very familiar, I think now with Zoom meetings. This is similar but it's not a Zoom meeting. It's a webinar everyone, all the attendees are muted except for the panel members. And you can't change that. And everyone, except the panelists' cameras are turned off. Near the bottom of your screen, you'll see icons for the chat function and for the Q&A. Keep an eye on the Q&A as we go. This is where you write your questions, or anything you'd like answered during the webinar. We'll keep all of the questions and answers until the end, that way, it doesn't break up the flow of the evening. There should be a function if it's working to vote up the questions that you like or that you would most like to hear answers to. And if people can do that, then we'll try to get to the most popular questions first.

Before I hand over to the panelists, I'd like to start with an acknowledgement of the traditional owners and custodians of the land we are on as the first people of this country. And that's an acknowledgement of the traditional owners wherever we all are attending this webinar. Here in Sydney, it's the Gadigal people of the Eora Nation and I pay my respects to elder's past and present.

So now I'd like to welcome our panel. First is Susan Jury, Susan heads up the Voluntary Assisted Dying Care Navigator team in Victoria. Then there's Alice Morison, who is the manager of the Voluntary Assisted Dying Care Navigator team in Western Australia. And then we also have Dr. Gareth Wahl, an emergency physician and member of the voluntary assisted dying community of practice in Perth.

And, of course, I'd like to welcome all of you who've registered and sent in questions, and who are here tonight. Just to let you know, we have received an absolute truckload of questions. Unfortunately, we won't be able to answer all of them tonight, but we will send out some information after the webinar, including a link to the recording of this webinar if all the technology works. And there will be some slides and things that we use during this webinar that will be included in that.

Before we go to the panelists, which is who we're here to hear, I'd like to give a quick introduction to voluntary assisted dying and the situation as it stands in Australia today. And I'll do that by sharing some slides that we've prepared.

[Slide1] Hopefully everyone can see that. So voluntary assisted dying in Australia... a brief definition of what it is we are here talking about.

Voluntary assisted dying or VAD gives eligible people diagnosed with a life limiting condition who are suffering intolerably and dying, and additional end of life choice by allowing them to choose the timing and circumstances of their death. So there are lots of different definitions of voluntary assisted dying. This one was taken from Queensland Health's VAD handbook, which has just recently been published

[Slide 2] The situation in Australia... so we have six states and two territories in Australia. Voluntary assisted dying is a health issue and that's an issue that is dealt with by the states, which is why we've had to pass six laws, six individual laws.

- Victoria was the first state to pass a VAD law back in 2017 and that law came into effect in June 2019. So it's been operating now for a little over three years.
- Western Australia was the next cab off the rank. Their law was passed in December 2019 and in Western Australia the law came into effect in July 2021. And so in Western Australia, that has been operating now for a little over a year.
- Tasmania was the next state to pass a VAD law. That happened in March 2021. And Tasmania's law will be the next one to come into effect from the 23rd of October this year.
- South Australia followed soon after in May 2021 and South Australia's law should be in operation from the beginning of next year. Fingers crossed it'll be the first of January.
- Queensland passed a law in September 2021 – 2021 was a big year – and Queensland's law will begin from the first of January next year.
- New South Wales was the last state to pass a law that was passed only a couple of months ago in May 2022. And New South Wales's law will begin from the 28th of November, 2023 next year.
- Voluntary assisted dying is still illegal in the Northern Territory in the ACT. There's been a federal law that has stopped the Northern Territory in the ACT from passing their own voluntary assisted dying laws. And if you were paying attention to the news this week,

you'll have seen that a Commonwealth law to reverse that situation passed through the lower house of federal parliament. It still has to make its way through the Senate. But we're hoping that will happen in September. Once that happens, the Northern Territory and the ACT will be free to introduce, debate and pass their own voluntary assisted dying laws if they see fit.

[Slide 3] So the laws have been passed in six states. There are strict eligibility criteria, however, to access those laws. All our laws follow a similar framework, which limits assistance to die to:

- Adults, so you have to be over 18.
- You have to be at the very end stage of a terminal illness.
- You have to have decision making capacity in regards to your medical treatments.
- And you have to be someone who is suffering in a manner that you deem to be intolerable.

All of the laws are similar, but there are some key differences to the laws, mainly around who can raise the subject of VAD, some of the residency requirements, and some of the timeframes involved in the law differ between states, but overall, very similar laws across the country.

[Slide 4] The key word there is at the beginning, it's voluntary for all involved. And it's asking for medical assistance to hasten your death. It includes two processes.

- The first is self-administration where the person takes the medication themselves.
- And in all states, there is another option, which is practitioner administration, where the person is given the medication by the health practitioner.

[Slide 5] The application process for VAD... each state requires a person to undergo a request and assessment process. And that generally involves a person making at least three requests for voluntary assisted dying, and being assessed as eligible by at least two independent doctors.

So that's voluntary assisted dying.

And the last of the housekeeping, I'll just remind people what this webinar is and what it isn't. So we have experts here from two Australian states, Victoria and Western Australia. And they're the two states where assisted dying is already in operation. So even though the panelists are from those two states, the information that will be presented will be general in nature. And it will apply to all of the states more or less. Wherever you are in Australia, the information here should be of benefit to you.

What we won't do in this webinar is go into specifics of the VAD process, and that includes the specifics of the medications that are used. There are quite strict criminal laws, actually, around talking too much about those specifics, so we won't be going there. And I just like to say, too, that, even though we have, you know, clinicians here medical professionals, this webinar is not intended to replace clinical judgment, or act as legal advice or give individual medical advice. And so the information is general in nature.

So that is the introductory part of tonight. Now without further ado, I'll hand over to the experts, the panelists. Alice, Susan, and Gareth, who have first-hand experience in the topic for tonight's conversation, and that's how to navigate voluntary assisted dying.

I'll hand over now to maybe Susan to kick us off.

Susan Jury

Thanks, Steve. And thanks for having us here this evening. It's a pleasure to be part of this. So I guess the first thing that Steve had hoped that we might cover is a little bit of an overview of who the navigator service is and what we are here for...

So we, as Steve mentioned, the law has been around in Victoria since 2019, so we've had it here for three years. And part of the implementation in Victoria was to put the Navigator Service in place. We're a team of healthcare professionals, so in Victoria we consist of nurses, social workers, and a psychologist. And our role is really to provide support when needed when people want to find out some information about voluntary assisted dying, or they want to get their way through the process.

The idea is to try and reduce the potential inequities in access when for one reason or another, a person may have trouble accessing appointments, knowing who the doctors are, who can see them, or other aspects that may be impacting on their access to care.

We also, part of what we do, and I'm sure it'll be the case in WA as well, is also making sure that people have access to other end of life care that they may need. We don't work in a little bubble, we work within a health service and everything we do is about trying to keep a person within their usual health care wherever possible, making sure that everyone has the choice to other health services they might like or need, for example, palliative care, potentially trials or access to neurologists, oncologists, etc..

We're not here to promote or advocate for voluntary assisted dying. VAD suits a small number of people towards the end of their life. It is an option, we always like to say that it works best when it's an option at the end of the life, it's not the focus. And many people... what we see, always, they the comfort that they can get from knowing that this is an option for them can be all that's needed and in fact, that enables them to engage much better in palliative care and other end of life services because they know that they've got this as a backup if they need it.

We work with the person who is seeking either voluntary assisted dying or seeking information. We work with people who are of course, likely to be eligible, but also sometimes people that may not be eligible, and they may be needing some kind of support and connecting with other services to support them. We also work with healthcare providers. So, we work with the usual care teams to try and give them the skills and the support and the backing that they need so that they can care for the person that they're caring for. VAD even in Victoria is still new for many healthcare providers. And when a person asks someone for the first time about VAD, it can be confronting for staff. And aged care, we hear sometimes carers saying what am I doing that's making this person want to access VAD? Why aren't I looking after them enough? What am I doing wrong? And so there can be some conversations about that to help staff find a place of peace. Sometimes staff have their own position and they don't support it. And so we'll work with an organization to work out how can we respect the person's request for assisted dying, how can we support their family but also how can we

support the staff and enable the staff to have their position respected as well.

We also work with the family. Sometimes, in fact, fairly often, a family may be in a very different position to the person seeking voluntary assisted dying. They may be grappling with the fact that the person they love or care for is facing end of life anyway, never mind throwing in the complicating factor of VAD. There may be cultural or religious or other barriers that are confusing things for them as well. And it's not uncommon for us to spend time with the person but also with their family. Often, that's more enabling the conversations to happen that might not normally happen without perhaps a third party there.

And then finally, we'll also work with the organizations. And it's a little bit less so in the case of Victoria now, but in aged care places, again, it can be the case that it's the first time they've ever had a VAD encounter or a person asking about VAD. So what policies or procedures do they have in place? Or was that policy or procedure written when it was all theoretical before the law came out? Now you've got a real person asking for this and it completely changes the theory. And so we'll kind of work with them to say how can we make this work. What will work? What won't? What can we do to support you etc?

So we do work with a whole range of people. And as I say, that includes people who are supportive of VAD, but it does include people who aren't. And often people who are sitting somewhere in the middle. I always like to try and avoid the terms where I can about being supportive or not supportive or participating or not participating. Because I think that, creating that, it kind of creates an us and them in some ways. And often people shift on their pathway as this becomes a real-life situation for them for one particular person or in one particular context. And it's a fluid kind of position. It's not as fixed as we sometimes tend to think.

And so before I hand over to Alice I hope it's all okay, what I'm saying. But I thought I'd give one example of a patient recently. And just to just kind of go through briefly what we did as the Navigator Service that gives you an idea of our role. Does that sound useful at this stage? Steve? Yep, happy?

We'll call this man Colin, and he had a progressive neurological illness. And he was living in aged care because his family weren't able to care for him at home due to his illness anymore. Very, very articulate man. He, his son was the one that actually contacted us in the first instance, because Colin could no longer speak due to his neurological illness. And his son was really emotional when he called us, he would be very tearful on the phone to us. He really wanted to honour his dad's wishes. He was the only son and he hadn't told his family about this. And he was holding this real burden on behalf of his dad of his dad's wishes. He was grappling with the fact of seeing his dad deteriorate and then now he was having to process the fact his dad actually potentially wanted to even end things sooner.

So I visited him in the aged care facility, I visited them both, Colin and his son. And we talked about the eligibility and the process and talked about where his son was sitting in the space. And we talked about the pros and cons, etc of discussing with his with his family and his wife. While I was there, I also met with the manager of the aged care facility, and it was their first voluntary assisted dying. She wasn't very clear on what their policy was. And there was a certain amount of staff angst about it. They weren't faith based, but many of the staff did have a cultural and faith-based background, that this was something very new and very confronting for them, at this point when it was first raised.

They were part of a broader aged care conglomerate. And so we had to discuss with the head office, which we did together, and talked about what their broader policy might be. And there was a lot of debate on their position on VAD. But eventually, they decided that yes, the assessments could take place on site. By great fortune, and I don't know if this kind of thing has happened just yet in WA, but his usual GP at the aged care facility was VAD trained. And so that took a lot of that pressure off of bringing in an external doctor in, but we contacted her and she came to the first assessment.

And we confirmed with Colin and his son about what documents were needed so they could arrange all of those, we arranged the specialist doctor as well, which is part of the legislation that two doctors complete these assessments, one of them in Victoria must be a specialist, and their illness. And then behind the scenes, in the coming weeks, there was some going in coming and going with the aged care facility, about the policy about whether he could take it on site, whether he couldn't etc, etc.

And so then we also developed with the family a plan B. So if he wasn't going to be able to take it on site, what else could we do, which in this case was that he would... his family, they really didn't want him to go home for this. And so it was engaging with a private hospital where he may possibly need to transfer for this. We worked with the VAD trained doctor to help to keep this process nice and smooth and carry on its way. And we kept in touch with the son to honor his dad's wishes, but also make sure that he had the support that he needed. We aren't the ones that give that support. We aren't the ones that do that but we are the ones that will be able to support the others to give that support. So we leave the counseling, for example, to the counseling experts.

And so in the end, with all of this coming and going, in the end, Colin did complete the assessment process. And he was found to be eligible, but he did actually die of his illness in the end. But as I mentioned before, the peace that he got from just knowing that he had this available to him is what mattered to him.

So that's my piece of talking. I guess, just to give a little bit of a wrap, is that our aim, as I mentioned, is to build VAD support into usual care not to be the go-to for everybody, not everybody needs to have the Navigator Service involved at all, and more and more clinicians in the community are very skilled to provide the support, but we're here for as and when that's needed. Thanks, Steve.

Steve Offner

Before I hand over to Alice, thank you, Susan... and I guess from the work we've done at Go Gentle with talking to a lot of families, and also doctors and other clinicians who've been involved in VAD, we hear nothing but praise for the care navigator services. And they've been described to us as angels, you guys have been described to us as angels. And I think that's because of the support you do give. Starting from the information that you provide as the first often the first port of call. But just based on what Susan, you were saying, it sounds like the Care Navigators are there to problem solve, as well. So I might now through to Alice, and she might want to explore that in a little more detail.

Alice Morison

I would love to. So definitely problem solving is one of our number one things. It probably sits, it's certainly before my 'angelic' qualities, I think, but we are certainly here to problem

solve. So if I think about the things that we can do for someone and what we do, so it's always tailored to the individual person. And I think what that example Susan has just given explains is the journey is often not quite so straightforward and there are a few things involved. So no problem solving about who you might want to talk to how that conversation might go, all of those things, definitely does form part of our role. But we will provide care based around what it is we hear from the person and their family and what kind of supports they're indicating to us that they need.

And we're very lucky to be the 'second child'. We did learn a lot from Susan and her wonderful colleagues in the Navigator Service in Victoria about how that might look.

We do things that go from everything from a single phone call from a person just seeking to understand what VAD is and whether it might or might not be an option for them at some point in the future, through to really walking with a person and their family, particularly their support network, throughout the entire VAD process. So that includes things like helping them find a doctor. So, you know, whilst it is amazing when we have a situation where a person's normal treating team is willing to step into that space and provide that care for that person that they know and have cared for often for a protracted period of time, sometimes that's not possible for a host of reasons. So we will certainly help patients to find doctors who have done the training, who are willing and able to accept their first request.

We help them problem solve with things like getting all the paperwork they need, you know, finding birth certificates to prove how old you are and that you are an Australian citizen.

Talking to the Department of Home Affairs about proving that you are indeed a permanent resident of Australia, you know, all of those sort of job-like things that people often need a lot of advice and support in terms of accessing them and having them ready. We do a lot of work around assessment and care coordination and Susan certainly spoke to the need to really make sure that this is part of a person's normal care. So VAD is not an island, it's not intended to be. It is an additional choice for a person at the end of their life. But it doesn't mean that you won't benefit from a continued relationship with the GP, a continued relationship with your oncologist and active engagement with palliative care.

But everyone's journey is really different. So we're often the glue that kind of brings some of those things together and makes this option available for people but not in and of itself, only of itself. We also... often we help people with actual assessment, so sit with them while they do assessments with the doctors, often when virtual care (telehealth) is required and that is something that we do as part of the process uniquely in Western Australia. We will help people find witnesses. Because often as part of the process, you do need to have a couple of witnesses involved. And usually that's a really hard conversation to have, if you haven't disclosed widely that you'd like to explore VAD. So we certainly assist with that.

We also are often present with the person when they die, whether or not they die as a result of practitioner supported administration or self-administration that Steve mentioned earlier. Sometimes it's just really helpful to have someone who knows what should happen because it's pretty scary thing to do, and particularly scary often for families who are going to be there afterwards and will want to know what's going to happen and how do I get help afterwards.

We do all of those things depending on what we hear from the person and we often provide quite a bit of support to families after the person has died just as a listening ear. But certainly, if you do need a bit more grief and bereavement support, then we're able to provide... we will

help you find the right people to go to for that kind of connection.

So it's a wealth of things that the Navigator Service does, varies person to person, very individual journey specific. And we essentially do that wherever it is that you are.

So there's a couple of questions in the chat, particularly around accessing regional areas. So the Navigator Service is designed to be a statewide service. So whilst we're based in Metro Perth, we do travel where it is people need us across the state and Susan talked in her case study about a particular person who struggled to communicate verbally, that's not unusual, often, face to face communication is a really important part of the person's journey. So if you're in Albany (regional WA), and you need us to come and see you, we will come and see you there. If you're in Kununarra (regional WA), we will come and see you there. And one of the unique things about our services is we provide care across public and private community aged care... I don't care what hospital catchment you're in, I will still care for you and I'll still come and see you if that's what you need.

Phone calls, emails, whatever it is that's needed at different parts in the person's journey, and supporting their family along the way, recognizing that often the family are really integral in making this work. And you heard Susan talk about the wish to want to support their dad's wishes. And that's something that we hear a lot, a lot along the way.

We're not doctors, though. So I can't take your first request, I've had a number of wonderful conversations that have begun with someone telling me that they would like to make a first request to me. Unfortunately, I can't take it. But I can help you find someone who can. So do always feel free to reach out to us if it's a conversation that you need to have. I can't tell you if you're eligible or not. But we can talk you through what the legislation is and acknowledge that that eligibility conversation really does need to happen when you meet with a doctor and they will do a formal eligibility assessment because only doctors who have done the training are in a position to say you are or you are not eligible, but we can help you work through what the requirements are.

Steve Offner

Okay, thanks, Alice. So, Gareth, that's a good segue to you. So as a doctor who is providing a VAD service, to your patients and to other patients, I guess, you know, sometimes the care navigators are the first port of call for people if they happen to Google, voluntary assisted dying, or they come across the contact details, but more likely, more likely it will be the doctor, the person's treating doctor or their GP who will receive the first request. So we'll get you to talk a little bit about that. But before you do, maybe, have you got anything that you could add to how the doctors interact with the care navigators and how the care navigators help you do your role?

Gareth Wahl

Frequently, is probably the easiest term to use. So I think this will be different for every practitioner who's involved in voluntary assisted dying, the level of interaction with different support staff like the navigators is going to be slightly different. For me, my usual place of work is the emergency department. It is therefore rare that I have any long-standing relationship with any patient that I see in ED as opposed to patients that I'll see for voluntary assisted dying work. All of the referrals that I receive, come directly from the Navigator Service or from my hospital coordinator, who's the person who fulfills the kind of navigator like role

within my hospital service. So I deal with the navigators a lot. And it's quite common.

And I think there's still this theme seeing the questions that are coming up of how do I access this care? It's not infrequent that patients will come and see me for a first assessment, having sought assistance from the navigators, but actually having made first requests, some of which will have been recorded as first request, some of which will not have been noted to have been first requests on many, many occasions before they actually get through to see me. That's a long-standing problem. And you know, it's... I think it is getting better, and how do we get around that that's about patients, you know, people like the people who are on this webinar tonight, who now know about the process that has to be followed and about how you can speak to the navigator team who will put you in touch regardless of what you get from your usual treating clinicians. Some patients will be lucky and it will be their routine GP just like the just like Susan was saying, there will be patients whose usual GP will have done the mandatory training to be to be a VAD practitioner, but that won't be the case for everybody.

In terms of why, why do I do this? I thought this was a good idea. I think this is a good thing. I certainly knew that there was a demand. All of these changes to bring VAD into law have been really demanded by patients speaking clearly, articulately and for a long period of time about what they want. And I find the hospital system really doesn't allow me to feel like I help people all the time. This does.

Why did I start doing this? It's because people really wanted it. And I thought it sounded like a good idea and something I would like. Why do I continue to do it because I find it immensely satisfying. It's immensely satisfying to be to be able to help people and be involved in those really intimate final moments with just their family and myself on a lot of occasions.

Why should other doctors do it? Your patients will ask you, your patients will categorically ask you. I know we've often said in our teaching around this, you know, whenever this was introduced in WA, we only knew what had happened in Victoria, we didn't have any other states. So we kind of thought that things might be different. As it turns out, we're just like every other place in the world where this has been made legal. We're seeing the same patients, we're seeing the same cohorts of patients. If you look at the statistics on who is accessing Voluntary Assisted Dying in Western Australia, it is the same demographics as the people in Victoria, it is the same people who are accessing this in every other part of the world. So GPs will have patients asking about this. Oncologists will have patients ask them about this. Every GP or every doctor who's in practice is going to get a first request at some point. And I think this is about being able to meet patients where they are and meet the needs that they have at that particular point in time.

Steve Offner

Thanks, Gareth. I was just looking at the chat box there, as you were talking and a colleague of yours, Simon Towler was putting some questions in the chat box, which I think are quite pertinent actually. So he's he made a comment that the care navigators seem to have taken on the burden of case management that maybe wasn't anticipated, before these laws came into effect. And I think that's probably why the service that the care navigators provide is so valuable, that these cases actually do need to be managed. So that's one thing Susan's putting her hand up. We'll come to you in a minute Susan. Gareth, but Simon also asked just as you were talking about a first request, he had a question there about how do you define a

first request, because if you're seeking to access VAD, and you ask or you bring up the topic with your GP, but your GP is not VAD trained, does that qualify as a first request?

Gareth Wahl

To be honest, I think that's almost less than the problem. I think the problem is not about whether people know that they need to fill in a form, it's about people understanding what occurs if you do fill in a form. So in Western Australia, and I can only really speak specifically about the WA practice with this. A first request is defined in the act as an unequivocal request for assistance die by a patient during the context of a medical consultation. So if a patient meets that criteria - that is a first request, every medical practitioner in Western Australia is required upon receiving a first request to complete paperwork, which is available on the WA Department of Health website, which is a first request form. If a person has not completed the training, and does not want to complete the training, then they are required to refuse that first request. But it does not mean a first request has not been made.

The difficulty is that lots of practitioners are not aware when they hear first request. A patient will go and very clearly say I want Voluntary Assisted Dying. And I think a lot of the people who are in this webinar are just like a lot of the patients that I see who are really clear and articulate and will tell you exactly what they want. So that's an easy discussion, these people know what they want. And so they will say that, but a practitioner will not be aware that they've got to complete that form, they won't fill in the form, or they'll fill in the form and think that a referral has been made. But a first request form here - and this is part of the complexity of how the law has been made - that the forms go to the VAD Board for reporting to the Minister of Health, and are a reporting entity who maintain data, but are not involved in clinical care.

So that first request form will be lodged, which is perceived by patients who are used to waiting a long period of time for care in our system and under the impression that somebody will then contact them, when actually that doesn't happen. So from my point of view, I think the bigger issue is not, you know whether people are eligible, I mean, there is an issue that there are not enough practitioners who are who have completed the training. But it's also just that those discussions are not had about, this is what I want, or this is what I don't want. And that's not ... people have fear or discomfort with those sorts of discussions, and they don't really go anywhere, and it doesn't get people to the to the point of care that they want.

Steve Offner

Susan, you wanted to make a comment. But I guess what Gareth was talking about there was the education role that the care navigators also provide. So not only to patients, but also to doctors. Is that right?

Susan Jury

Yeah. Yeah, that's true. And I guess what I what we've kind of observed in Victoria, is that, exactly like Gareth was just saying that often, when a person raises something with a doctor, they think that something will happen out of that. But that isn't always the case. And the legislation is very much designed to be driven by the person. And then that requires courage sometimes, it requires courage and perseverance and a certain degree of being well enough to advocate for themselves on the part of the person, which sometimes doesn't sit well in the

space. And I guess one of our kind of, you know, when you're talking about some of the tips for people trying to access VAD, absolutely make that first request to your doctor. But I would also say, also contact the navigators. The navigators might have no role to play, because absolutely, something might come out of [the first request] And there's nothing else to happen, but at least they don't think that they're waiting for something to happen and then they get really unwell. And time has, really important time has passed before you can start this process. The process in Victoria takes around about four to six weeks is what we usually say. And that can be a fairly meaningful four to six, fairly significant four to six weeks, when someone's at the pointier end of being towards the end of life.

The other thing I was going to mention is the comments that you raised from the chat about the care navigators being case managers. And over the course of three years, what I see is that that's starting to change. At the beginning, when it's so new for absolutely everybody, the navigators play a very much hands-on role. But you might find that over time that changes as there's more and more doctors who actually can respond to that first request, they know what to do, you encounter someone like Gareth very easily, they've had lots of... doctors have had lots of experience and then there's less and less of a role for us. Because the broader health services have got more capacity, and skills.

Steve Offner

So look, I think there's a couple of points there, too, in our discussions with families and doctors, one of the things that we hear a lot is at the beginning of the process, when patients are exploring this as an option and perhaps making their first request, the frustration whereby they haven't asked the right question, or they haven't asked the right person in the right way. And they feel like they've just been going around and around in circles. And so I think, Susan, your advice, to also contact the care navigators is probably a very good piece of advice there. And I think also your comment that this, you know, in Victoria, at least I can't imagine it would be much different in Western Australia, that it takes on average between four and six weeks. That this is not meant to be an emergency procedure, that it takes time. And I guess... what's your advice for people who may be contemplating this as an option now to try and avoid some of those time delays?

Alice Morison

Yeah, yeah. So I think there's lots of things that you can do in this, you know, sort of funny Twilight Zone period where you're thinking about this, but you're not quite sure if it's something that you want to do or you're ready to do it. Certainly we've talked about paperwork a couple of times. So familiarizing yourself with the things that you might need in terms of documentation, because requesting things like proof of residency and birth certificates and stuff does take time if you don't have those things ready to hand. The other thing we really encourage you to do is to start to have conversations with people about it so, often we find people don't want to tell everyone and that's absolutely okay. It's really personal choice and a very particular choice but, you know, to perhaps talk to your nearest and dearest and definitely consider having conversations with your treating team, your GP or oncologist, your hematologist, your consultant and whoever it is that you that you would normally see for care because they will continue to be involved in your care and even if you're not eligible yet as this helps their understanding that this is something that you're thinking about is really important because it helps them recognize what's important to you at the end of your life and that things are not okay right now.

In terms of timing about when to start, so it is a really difficult question. And Susan highlighted the fact that, you know, it takes time and waiting until you're in the last sort of couple of weeks of your life, will make this really challenging and you'll probably have other things that you want to do with that time that don't involve meeting new doctors and having complex assessments and transferring around. So if this is something that you're interested in exploring, we'd really encourage you to seek some further information as soon as you feel ready to start thinking about whether or not this is right for you. There's lots of ways to do that. Absolutely you can contact the Navigator Service.

And it's not unusual for us to have a conversation with someone today, and then not hear from them again for six months, because what they wanted was solid information to think into planning to consider and then come back to us later. You can Google... both states where the legislation is available have websites that are available with sound information from the Department of Health, some of them are tricky to navigate. Again, if you can't find what you're looking for, give us a call and we'll help you out. But we would really encourage people not to wait until they want it right now. Because it will not happen overnight. There are particular things in our law in terms of timeframes required for the process. And I know there's a number of questions in the chat about timeframes, and that it seems really hard. And it certainly can be tricky to work through quickly, the navigators can definitely help you. We're lucky in Western Australia, and that we can use telehealth and we have a couple of different things in our legislation, which make things often a little bit faster from time to time. So we can generally find people working through the process, if they want to keep cracking on in about three to four weeks. But it's a very individual and very personal process. And some people want to crack on through as fast as humanly possible. And they'll be saying is urgent, urgent, urgent, urgent, urgent, I desperately want to do it. And they'll get halfway through the process and go, oh, I need a breather. And that's absolutely okay. Because it's your journey, and you take it when you're ready. And then we have patients who just want to work their way through slowly over time. And I think that comes back to what Susan mentioned earlier about just knowing you have it available to you was an option. For many people, it's just an escape hatch. No imminent plans to use it, just want to know that it's there as if and when I need. And if timing is a question for you, just call us and have a chat. We'll help you work it out. But really, it's very person specific. And with good information, you can make good choices about when's the right time for you.

Gareth Wahl

Can I say something about the timeframe thing? It seems like an opportune time to kind of mention that. I've kept records of sort of the duration of time that I've looked after patients in this space and there's certainly, the WA law probably makes things a little bit easier in terms of going through the process than Victoria and every state will be slightly different, which is why I think the central point of information for any particular state should be the Navigator Service for that state, because they are going to be particularly at the point of the law being enacted, they are going to be the experts in terms of how this works. In Victoria, I guess there's the roadblocks of having to seek permits at different points. In Western Australia, we're allowed to proceed straight through the process as long as the practitioner will certify in good faith that the person has met all the requirements.

So in Western Australia, the minimum period of time that can elapse between a first request and a final request is nine days. And we are allowed to shorten that. So as Simon has already

mentioned in the chat, if the coordinating and consulting practitioner, so the two independent doctors that have seen the patient, both agree that the patient is likely to die or lose capacity within that nine-day period, that period may be abbreviated. And all states have created similar sorts of abbreviated processes for patients where there is a risk of death. But that's hard. I work three days a week in ED, I'm not available then for those three days. All practitioners will be working at different times and I will hand on heart go out of my way to try and make things happen for you if it's absolutely needed. But life gets in the way. I had COVID last week, you know these things are real challenges that we will come up against. And so I absolutely agree with you Alice. It's that thing of being... yes, I have had patients who have completed this process from first assessment with me, maybe not the first time they've ever spoken to somebody about it, but the first assessment with me through to dying by VAD administration within a period of two weeks. That's not uncommon. But I've also had patients where I've looked after them for many months, many months, and we go through whatever process the patient wants to follow. Some people like to just have, you know, to... You know somebody who's involved in VAD is often then somebody who's willing to be involved in discussions around 'how you stop treatment if you don't want to be on treatment anymore', 'how you do all of these sort of end of life experiences that people have', treatment treadmills that people find themselves on and trying to get off that, how do you do that. I actually find that I spend a relatively small part of my time talking about voluntary assisted dying specifically, and actually spend a larger part of time talking around all of the things that are adjacent to that.

And one other thing about timing I'd like to say is that patients, once they are found eligible, they do not cease to be eligible. So I am required to determine in Western Australia that a person is on the balance of probabilities likely to die within six months, unless it is a neuro-degenerative problem, in which case death may be within 12 months. There are patients who have unpredictable conditions, who have say metastatic cancer, who are on their last line of treatment, and it looks like things are not going well, who will subsequently be found eligible for a trial, which may have remarkable results. That person can continue to be eligible [for VAD]. Even though that period of six months has lapsed, that person doesn't go through the assessment period again. You go through the assessment period once and you are through the assessment period.

Steve Offner

Thanks for that, Gareth. So in summary, then I guess, you know, when we said that voluntary assisted dying is not designed to be an emergency process or emergency procedure, there are there are ways that if it needs to be expedited it can be and so people shouldn't be too concerned that if events overtake that application process, then the process can be sped up. And I guess the other take home message from that is there are strict timeframes within the legislation for the assessment, the official assessment process, but I guess the application process can start earlier than that, when we're talking about gathering all the paperwork that you might need, for example, and having those conversations.

So maybe if we now work our way through some of the questions that were sent to us before tonight's webinar.. One of them was a question about what paperwork do I need? So without going into too much detail, what kinds of paperwork do people need to have to prove progress through this process? Alice or Susan?

Susan Jury

Alice has talked a bit about the paperwork already. So I'll have a turn on the paperwork...

[You need] something to prove that you are an Australian citizen or permanent resident, so that could be an Australian passport, an overseas passport that has an Australian permanent residency visa in it, a printout from VEVO [Visa Entitlement Verification Online], which is online immigration, to show that you are a permanent resident. And that can be Googled... or birth certificate. Now, the catch with the birth certificate is that if you're female, and you've been married, and you've had a name change, you also need to show proof of that name change i.e. marriage certificate, birth certificate, Birth, Marriage, Divorce certificate, whatever is needed to show the name change over time. So that's to prove being Australian citizen.

You also have to prove residency in the state. In Victoria and it looks like it's the same in WA, something to show that you've been living there for 12 months or more. So that could be a utility bill, a gas power bill or something like that, a bank statement. And again, talk to your navigators per state, about what's specifically accepted and not accepted in your state. Sometimes the driver's license is accepted, but there are kind of a few rules around that as well.

Also clinical information... so one thing that can be really useful is over time to keep a collection of your clinical information. If you're having a blood test, or if you're having imaging, if you're having scans, that kind of thing, keep you keep a copy of your results. If you get letters from your specialist visits, keep those letters and get all of those in order because imagine... an independent doctor who has never met you before is going to do an assessment for your eligibility for VAD and they need to have some good clinical information to support their decision.

Steve Offner

Alice, did you have anything else to add?

Alice Morison

No, the clinical information is gold. And again, that's often something we help people to get from their GP from their different specialists and things but we try quite hard to make sure that everything is there in readiness to help support the practitioners like Gareth to do those assessments and to determine whether or not someone's eligible, and often that's an important part of having conversations with your GP, and your oncologist or whoever it is - I feel like I'm picking on oncologists tonight - but to make them aware that this is something that you're thinking of, and that we've got everything that we need to help make that assessment process as smooth as possible.

Gareth Wahl

Sometimes it's gonna be really hard, you know, the system set up to... every system is slightly different. So Western Australia, we're in a really lucky situation of most public hospital blood test results, imaging results, and a lot of outpatient letters are all on one platform that we can all access. That's very different to most of Australia, where everything may be on one particular or network's information system, but there's so many different silos of information kept differently. How do you get around that? Your GP will generally have a lot of your information, hospitals will send information from whenever you see an oncologist or you know,

cardiologist... a discharge letter, or a clinic letter will be sent to your GP. You might never see that and you may never know that's occurred but it will be done. So you can often get a lot of this information from your GP. If your GP doesn't have it, or you don't, you can't speak to GP because of their conscientious objection or just general difficulty, the Navigator Service in your state is also going to be familiar with the setup of that health system. And they're going to know the ways to access that and have the ability to request permission through Freedom of Information if needed.

So you, I guess my key point is this whole thing could be summed up by one thing, speak to the navigators, who will, who will walk you through these, they've walked me through it, they will walk you through this, in terms of being able to access the information.

Steve Offner

Okay, we'll move on to another of the questions. It's also to do with the process. So, Bob from South Australia was asking specifically, can a guardian ask for VAD on someone else's behalf? That's one thing. But the second thing also, can a guardian, do some of this grunt work with the paperwork and the collection of records on behalf of someone? Maybe Susan, would you like to answer?

Susan Jury

Yeah Sure. So there's two kinds of answers to it. When it comes to someone advocating on their behalf and contacting the Navigator Service, then yes, someone else can do that on the person's behalf. Whether that's the Guardian, family member, friend, it can be anybody. We're happy to take calls from anybody because we recognize that sometimes the person themselves isn't in a position to make that call, for a range of reasons. When it comes to the doctors and doing the actual VAD assessments, the person themselves has to be able to make that request for themselves. If they aren't able to verbalize... people, in my experience, they have a way of communicating in some way, whether it's through a voice to text, texting app, or whether it's an eye movement app or other ways that people have to communicate, they will use it to communicate their wish to the doctor but the doctor absolutely has to hear that from the person themselves and Gareth will be able to talk to it. It's to make sure it's really this person's request that someone else can definitely advocate on their behalf, get the paperwork together, contact, make appointments and do some of that behind-the-scenes work.

Steve Offner

And Gareth maybe you can also talk about telehealth here, and whether some of those consultations are allowed in the process.

Gareth Wahl

Okay. Yeah. Yes. So the telehealth, I use it all the time. I think we've all become very familiar with doing visits over telehealth, and it's one of the great, one of the good things that have kind of COVID is that the health systems generally have become much more au fait with doing assessments and have created platforms that will allow us to do that easily and confidentially and securely. So, there is a requirement, I did see a question come up about something similar to this, about do I see patients just by video conference? No, is the short answer, but kind of. So I will often.... there are some occasions where I will do a first assessment over

video conference. It is I would say less common that that would be my first way I would meet a patient because I... to be honest, it's I find that the rapport and the interaction is generally more satisfying for both parties when it is face to face. I try not to do first assessments by video conference, but WA is a very big place. There are certainly patients who I have seen for the first request and first assessment by video conference, because logistically, that's the easiest way for that to occur if you're a couple of 1000 kilometers away.

The law does require though, so there's, I don't want to bore you with the Commonwealth Criminal Code. But there are certain things we cannot discuss over carriage medium because it's illegal. And that all is to do... or maybe illegal. We don't know if it's illegal, because nobody's been charged yet for us to go to court and find out. But talking about suicide is illegal through a carriage medium so that limits us being able to talk specifically about medications and how somebody might take medication and all those sorts of things. So, I cannot in good conscience complete the entire process of assessment of a patient for voluntary assisted dying through a carriage service, including video conference regardless of how secure it is and whether you want to or not. So I always see a person physically at least once during that process, and generally I would say that I see people many times physically during the process unless they live a very far way away and travel is difficult.

I mean, video conferencing and teleconferencing is... it absolutely has made our lives so much easier and has reduced any regional impairment that patients might have. And I think that's a really good thing about the WA law is it's that focus on minimizing any impairment that regional or disability that regional patients find themselves in, and that's through the Regional Access Support Scheme as well as the ability to use teleconferencing.

Steve Offner

Yeah, Susan, how's that played out in Victoria? Because there were some extra concerns in Victoria, right, about the use of telehealth. The Victorian law does not explicitly say that voluntary assisted dying isn't suicide.

Susan Jury

That's correct. And so it is slightly different in Victoria. So any of our Victorian audience it is worth knowing that appointments do need to take place in person in Victoria at the moment. So sometimes that requires, ideally, sometimes it requires attending a doctor in clinic and so being well enough to get to a doctor in clinic. We do have doctors that do home visits, but not necessarily to all parts of Victoria, or necessarily for all illnesses. And so that comes back to the comments before about completing this assessment process as close to your eligibility timeframe, your six or 12 months as possible, while you're still able to travel for appointments.

Steve Offner

Yeah. And look, we could spend all night talking about the Commonwealth Criminal Code and telehealth. Suffice to say most, or actually, every state after Victoria has somewhat dealt with this issue, by writing into their legislation, that VAD is not suicide. It is untested. Every state is now lobbying the federal government to clarify this. It's a very simple thing for the federal government to do... all they need to do is a very small change to the Commonwealth Criminal Code to clarify that, that law does not apply to voluntary assisted dying. And we un-

derstand that there may be some very positive movement on that soon. So we might move on from that. Just one other thing. One other question that's come in about the process. And surprisingly, it comes up or maybe not surprisingly, quite often, is how much does it cost a patient to go through the voluntary assisted dying process? Alice?

Alice Morison

We have this all the time. And it's a really important conversation, because whilst money's not everything it is actually something people worry about a lot in the healthcare space. So certainly the care navigator service is funded by the government so apart from in your taxes, you pay nothing for us, regardless of how little or how much you use us. And if I need to spend eight hours on a plane to get to you, then I spend eight hours on the plane to get to you and there's no cost to the person in relation to that care we provide. Our pharmacy service, the statewide pharmacy service who dispense the medication, I know there's a couple of questions about that., it's not something that you can get from your local triple seven [Pharmacy 777, a chain of chemists in WA]. The statewide pharmacy service is free of charge as well, including if they travel to the person to dispense which they absolutely do in Western Australia for people who choose to self-administer. So all of the statewide services are essentially completely free.

Practitioners can absolutely charge a fee for their services. So just like going and seeing your doctor, they are entitled to charge a fee. These are doctors who have spent considerable amount of time training as medical practitioners and need to be very experienced at consultant level like our fabulous Gareth to be able to provide this care for you. And we pay when I go to my GP to get a script there's an expectation that I'll pay them for their time. So, certainly, they can charge a fee for their services. They don't get a great deal of remuneration back from Medicare... and I noticed some questions in the chat about MBS funding and that sort of thing. I think one of our doctors did some mapping and usually, if they're coordinating, so the primary doctor who's caring for a patient throughout the process, they usually spend somewhere between 10 to 14 hours caring for a person. A lot of that is face to face, but it may also be a lot of chasing results and seeking clinical information and other opinions and things like that. And usually about two hours of that is billable through Medicare. So please do be considerate when you're asking your doctors to provide this care because sometimes it's actually just financially not viable for them to do it. But I know all of our practitioners, if you are concerned about costs, we really encourage you to have a conversation with them and they will do everything they can to support your equitable access to this.

So please raise it with the doctors if you're concerned. And you're certainly welcome to have a conversation with the navigators as well. We do we also have... Gareth mentioned the regional access support scheme that funds practitioners to travel to patients in rural and regional areas of Western Australia... that pays for the practitioner's time to get to you in terms of remuneration for lost earnings but there's a slightly different model that the Victorian crew have available to them.

Steve Offner

Yeah, and I think, you know, we could spend a lot of time on this. It's a topic... it's a very important subject, the proper remuneration of doctors who provide their service. And again, there are conversations happening at the state level and with the Commonwealth. And we're

hoping that there will be some movement on this as well, specifically in getting voluntary assisted dying included in the medical benefits schedule. So watch this space.

We'll move on, we've only got half an hour to go for some questions. We'll move on to another question that came in beforehand. And it's one that's increasingly being asked, and I think that's because of some of the developments that have happened in other states. And this question is from Robert, in WA, and it was asked by a number of people actually, and it concerns non participation by institutions and doctors. And Roberts asking, how does somebody who wants to access voluntary assisted dying, determine which doctors are willing and trained to provide the service and also, which faith-based facilities are likely to either assist or obstruct your access to voluntary assisted dying? So I don't know who wants to tackle that one. Anyway, I'm going to volunteer Alice...

Alice Morison

Yeah, it's a WA one, so we should probably take that. In essence, again, I would encourage people to have conversations with their treating team, because often GPs in their busy lives that they have, and you know, the current COVID climate and all the pressures on them, they may not have actually thought about doing the training or making time to do the training to support someone in this space, until you're sitting across from them, asking them for their help. So I would always suggest, if you're comfortable, to have that conversation with your treating team. If you're not ring us and we'll help you find a doctor. I can't promise you it will be Gareth. But we'll do our best to find you someone who is a good fit for you who's able to support you through that process. So do reach out as you need.

Faith-based services come up a lot. Susan mentioned that the navigator services spend quite a bit of time working with different health services and providers. And certainly, we have worked extensively with our faith-based crew. And we have a really great relationship with them. And a really clear understanding about what we can and what we can't do on their sites. Some of them have got public positions that you can find. So if they're services that you're likely to engage with, I would encourage you to have a look on their website. And you can talk to us about that as well. And you can also talk to your care providers, if you're concerned that that might not be something that will not be available to you there. In general, the navigators can see you, wherever it is, where you are, we will come and visit you. What can't happen generally on a faith based inpatient hospital setting is doctors coming in to do the assessment. You'll often need to leave the property for those things to happen, but they're really general principles. And I would always encourage you have a conversation about that.

Gareth Wahl

There's an interesting point that Susan raised before about the... it's very... a lot of places will have policies and then when you are confronted with a person in front of you, those policies will sometimes change. People find it hard when you have a real person in front of you as opposed to some creature in a text document. I think a lot of the stuff about... these things... these questions about the Who do I avoid?... is all about people not wanting to have uncomfortable discussions, and I absolutely understand that. These discussions can be really uncomfortable if you get into it and you find actually you you're engaged in some sort of... you feel like you're in a war that you didn't want to be part of.

I would say most of the time, I have a couple of principles about what doctors are going to think. Number one, you are probably not the first person to talk about Voluntary Assisted Dying. It might be really awkward and feel uncomfortable for you. But it is probably not the first time that doctor has been asked about that. We are often asked about things that run very contrary to our own beliefs, morals, values, and then it's just a part of being a clinician that you deal with that. The other thing I would say is if it really if it has reached that point where you're so worried about, you don't know whether this how this discussion is gonna go, and you don't know how to raise it, you can ask the navigator service, I feel like I'm just sending everybody to you and creating extra work. I'm sorry, guys. But we do this, we do this all the time. And they do this all the time. And they will deal with a lot of the practitioners in Western Australia. And if your oncologist is going to, you know, no oncologist is going to stand and yell at you. But if you're really worried that they are the Navigators probably know your oncologist or know of your oncologist and can give you some idea as to what they're going to think. So if you're really worried, and I think that's where all of these things come from, ask us. And we'll let you know.

Steve Offner

These questions when they come in, they're often accompanied by a related question, is there a list of institutions and doctors? And correct me if I'm wrong, but is it fair to say that Yes, there are lists, but they're just not publicly available?

Susan Jury

I can answer that if you like. So we are quite strongly of the position that we don't have a list as such. We know who... we do know the position of many different doctors and organizations. And we can connect you with the right person or the right organization. But like Gareth was just saying, then positions can change a lot. So having a list is such a fluid thing, that it's not particularly helpful. And also, we're very respectful of doctors' right to privacy as well. And doctors don't necessarily want to have their names out there on a publicly available list. And we are very considerate in the way that we would connect people with the right doctor, for example, in Victoria, a doctor who's willing to administer so practitioner administer if that's what's required. Not all doctors are comfortable with that. Or a doctor who's happy to home visit, if that's what's required, etc. But it's not like we have this list that can be sent out there. And we don't we don't think... we don't want that either.

Steve Offner

Fair enough. We might move now to some of the questions that came in about eligibility criteria. And again, one of the big questions we get asked all the time is about non eligible conditions, what conditions are making you non eligible for voluntary assisted dying? And I guess, the big one there, the question we're asked more than any other is dementia – Alzheimer's and dementia – and other diseases where you may have lost capacity. So what is the situation... you guys must get asked this all the time, and you must be confronted with these cases all the time. Is there a simple rule of thumb?

Susan Jury

Gareth, you're the best placed of us three to answer...

Gareth Wahl

So look, every state in Australia that has legislated for this has created exclusion criteria and said that a person cannot be found eligible on the basis of a disability, or mental health or mental health diagnosis. They cannot be... you can have those and be found eligible but you can't be found eligible on the basis of that alone. Other than New South Wales, which has added into the legislation, which is not in action yet, but it is in the legislation that you cannot be found eligible on the basis of dementia. No other state in Australia has created in the legislation a specific exclusion on the basis of dementia. Having said that, it's difficult because if a patient has cognitive impairment, they that would be a neurodegenerative problem, it would be generally perceived to be a neurodegenerative problem and so it would be required in all states that that person will be found to have a prognosis on the balance of probabilities of less than one year [to live]. And that's a difficult balance. That's a difficult burden to meet, to have to have dementia and be found to be on balance of probabilities likely to die within one year and still have the capacity to request freely, Voluntary Assisted Dying.

Does it mean, though, that you can be found eligible with dementia and another condition? That's quite common I'd say, not, you know, it's not the norm, but it's not uncommon for me to have patients who have dementia, as well as cancer, or dementia as well as end stage heart failure or COPD, or some other condition that they are likely to die from. And the fact that that person has dementia in Western Australia does not prohibit them seeking and gaining access to voluntary assisted dying.

Steve Offner

And the other big question we're asked often about eligibility, involves some of the chronic conditions, where you may not have a terminal diagnosis or a prognosis. Are those people eligible for voluntary assisted dying? I think there's a very simple answer there. Gareth?

Gareth Wahl

Yes, so I think it depends on what the chronic condition is. So, we have to reach a prognosis on the balance of probabilities, that is what is required of us. So, if it is not possible to reach a prognosis on the balance of probabilities, then no person cannot be found eligible. These situations, I would say, generally are few and far between.

So certain things are allowed to be taken into account; a patient's treatment decisions are allowed to be taken into account in terms of determining their prognosis. A person who has a cancer that is eminently treatable, but chooses because for them the right thing is not to have treatment, or that may have a prognosis that is at diagnosis, they likely don't, but they may have a prognosis of less than six months, even though it may be longer than that if they had treatment. Does that mean that people should not have treatment? No, I mean, I think I fundamentally I do this because I want people to live good, long, healthy lives the way that they want. But what's right for me, it's not going to be right for everybody. And it's, you know, it's right, that we all get the right to own choices.

Chronic conditions like depression, though, I mean, yes, that that question gets asked all the time, can a person be found with depression, which has a, you know, you can do statistics and look at the epidemiology of the lifespan of somebody with chronic treatment resistant depression. Fundamentally, that is outlawed under all of the acts in all of Australia – person is not able to be found eligible for voluntary assisted dying on the basis of a mental health condition.

Steve Offner

And that would be the same for somebody who maybe was tired of life, had reached a certain age and no longer wanted to live?

Gareth Wahl

And I find I find those situations really upsetting. I mean, upsetting maybe, maybe too strong, but it's, I feel very frustrated, I feel, you know, I feel upset for those patients, because I have seen a number of patients who are tired of life and are in their 90s, and they are they, you know, they are tired and they are done, they want to die. Because that's what's right for them. But they again, they are not able to be found eligible unless there is another condition that can reasonably be found to have prognosis of less than six months, or 12 months depending on where you are in Australia and what the condition is.

Steve Offner

Okay. Another question. This one from Rebecca from New South Wales was about advanced care directives, can voluntary assisted dying be included in an advanced care directive? Alice?

Alice Morison

Love to. The short answer there is no. That doesn't mean that you shouldn't have an advanced care directive. I think particularly when you consider the patient cohort that we were just talking about, about people who may not be eligible to access VAD, having those things in place, makes your wishes really clear should you be in a position to not be able to express them yourself and to make decisions in relation to your treatment in advance. Your family don't have to try and work out what it is that you would have wanted, if you could talk to them. So they are hugely important. But all of our legislation requires a person to be able to make decisions in relation to their health at the time they are seeking to access VAD and must have that throughout the entire process. That's key capacity point that we've talked about, briefly a couple of times throughout this conversation. So, unfortunately not, that we won't be able to proceed with something that's written in an AHD [Advanced Health Directive] or an advanced care plan and that is a really hard thing, particularly you know, when we talk about patients with dementia and that sort of caper, but I would ask that you consider it from the doctor's perspective as well. So you'd be asking for someone to proceed with voluntary assisted dying when you couldn't look them in the eye, couldn't say to Gareth, this is what I want. And this is what I want right now, which is a really big thing to ask. So, certainly, some other countries are exploring it, Canada has just built in some waiver processes so people can do that. And maybe we will get to that point as well. But at the current time, no, you can't put it in an advanced care plan or advanced care directive.

Gareth Wahl

Can I just add one thing on to onto that kind of adjacent is that it's been mentioned in the chat questions... what happens if I have a catastrophic stroke and I cannot speak? How does that work? I would say that that is covered in the legislation, communication can change over time. So the mode of communication that you have with a patient when you first meet them, so motor neuron disease is probably the best example of this, where a person may be fully verbal when you first meet that person and have a first request and may be completely unable

to speak by the time of choosing administration. Patients can have strokes or other events that will impede their ability to communicate clearly, eloquently and articulately. And what I would say to people is you're not required to write an essay to tell me what you want. You can tell me, you know, at the very beginning, and this is the benefit of being a coordinating practitioner that follows a patient's trajectory over a period of time, is I have heard clearly and repeatedly what you want. I then hear that, I might hear that in a different way when it comes to the point of administration in a person who is unable to self-administer. But if it is able to be made clear what your request is, and we can be clear that there is a clear, voluntary, uncoerced request that is allowed.

Alice Morison

I just wanted to add to it, we've had patients that can only communicate with eye movement the whole way through the process. So please don't think that if you can't talk to us, even at the early stages, this won't be an option for you. Because what we need is to be able to hear you clearly communicate your wishes. But our practitioners are generally incredible at recognizing that people do that in a whole host of ways. It can be through gestures, it can be through eye movements. Susan mentioned things like text platforms, there's a whole host of options. And I have to say we've used hordes of different ones. And certainly, some of the clearest patients I have ever seen have been ones that have been only able to communicate through your gestures, because they're used to using that as a mechanism to get their message across.

Steve Offner

Right. Look, a similar question, I guess is – it came up in the Q&A tonight – was the issue of people from culturally and linguistically diverse communities. And some people who don't have English as a first language may need an interpreter with them. I guess the question was, you know, is this allowed and how does that go through an assessment when there's an interpreter involved? Gareth, have you had experience with this?

Gareth Wahl

Yeah, I do. So yes, I've seen patients with an interpreter present face to face. I've seen patients with an interpreter via telehealth. The telehealth ones have been ones where the patient was being seen by telehealth so you have people in three locations and yay the wonders of the internet. Does it create a barrier? Yes, it does. It creates a barrier when the care that you're seeking to access is not in a language that is acceptable or usually used by you. How do we get around that? We, the navigator services will generally facilitate these consultations with an interpreter. So there is generally no out of pocket cost to the patient for the care being delivered in a language that is appropriate for them. And that goes through all of the mechanisms. How does that look? Is it more challenging? Yes, it is more challenging. I think. It's hard when you are, but to be honest, I would actually say it is challenging having a consultation for an interpreter. I mean, it's an additional complexity, but it's not a complexity that I'm not familiar with. To be honest, it's easier than what I do half the time in emergency where I'm seeing somebody at two o'clock in the morning and the best that I have is a phone interpreter where there is that complete lack of face to face, that complete lack of nonverbal communication which you get through, you at least a little bit of through teleconference.

The thing I find difficult is people where there's a kind of the in-between and there are patients whose families will want to assist with communication. And that... we are all very alert to the potential for coercion and wanting to exclude categorically the potential for coercion. And what that means is that I am much... if there is concern about a patient's ability to articulate for themselves independently, I would much rather have an interpreter there, rather than use family. That creates some difficulties, I guess in terms of yes, you're introducing another third person, and there is this concern from people about how they will be perceived and all these sorts of things in small communities where there might be a relatively small number of interpreters. That again, the way I would get around that is big telecommunication, where you could potentially use an interpreter for an interstate area rather than a local interpreter, if that was culturally going to be for you. It does create a barrier, but I think we have tried, I say the royal we, have tried to get around that. And, generally, there will not be a cost to the patient for that access being provided.

Alice Morison

I've just been answering a couple of questions about interpreter services in the chat. But certainly, they've been invaluable to us. And we have certainly done some work with some of our service providers in this space about understanding what interpreters would want to know ahead of the conversation, including where is the person at in the process, because I think there was a bit of fear at the start that if we asked for their help, they'd be turning up for an administration, which was mildly terrifying. But they have actually added incredible value to the person's journey to the point where we had an interpreter, in fact, we've had a couple, where interpreters have been present when the person has died. And that was a conscious choice on behalf of the interpreter, because they wanted to ensure if the person had any last things they wanted to say that they were able to have a voice, and they've just been an incredible gift to us, you know, acknowledging all of the challenges that there often is within that three way person communication.

There are a number of resources that can help people doing work in that space. And we certainly published glossary of terms that we shared with our interpreter service agencies we often use so that the interpreter can have the opportunity to have had a look at those ahead of time, because we use weird and wonky language. We've been talking about coordinating practitioners and all sorts tonight, that allows them the opportunity to be familiar with those and the languages they would normally interpret for. So they've got some time to think ahead of time before they have a conversation with the patient in this space.

Steve Offner

Susan anything to add? Okay, we've only got a few minutes. And I do want to quickly go through the Q&A. I think we've answered most of the questions, but I do want to do that. But before we do, and this is one of my favorite questions only because I have no idea what the answer is. And it was submitted by Cathy from New South Wales, and it's to do with pacemakers and VAD. And surprisingly, you've all said, you've all had experiences with this. But Gareth, maybe you'd like to answer this? Does having a pacemaker get in the way of voluntary assisted dying?

Gareth Wahl

Not at all, is the short answer. So defibrillators, yes, we would deactivate a defibrillator. People will often have I mean, it used to be just single lead pacemakers. Now you can have every variety of wires under the sun that you want. But if a patient has a combined defibrillator, pacemaker/defibrillator the function should be deactivated. But a pacemaker, No, we're not, will not stop us doing things. A pacemaker is a machine, it sends out some electricity to a specific area of the heart to tell the heart when to beat. If the heart has died, because the body has died, the heart is unable to respond to the electricity. A pacemaker cannot keep you living eternally, if you have died. So the same way when a person dies, through any other means, their body will go to a funeral director who can remove that pacemaker and that pacemaker is just a little incision on the chest. That pacemaker can be removed prior to cremation, if the person would like. It's the same thing, that pacemaker is still active, but it cannot trigger the heart because the heart has died.

Steve Offner

Okay, thank you. I'm just scrolling through the Q&A, because we do only have a few minutes left. There's a question here... 'how do we access the care navigators?' I'll be putting up a slide at the end of this webinar with some of the contact details and there will be the QR codes included in that. So if you've got your phone and your QR reader handy, you'll be able to scan those QR codes but we'll also send all of that information out in the follow up email early next week.

Some of the other questions here... there was a question about the implementation period. So maybe Susan, you might answer this. You all work within a health system. And you've all in some ways been involved in getting voluntary assisted dying up and running in your states. Why do we need an 18-month implement implementation period, between the passing of the law and the law becoming active?

Susan Jury

The more preparation that can be done, the smoother, it's going to be on day one. And there's many people that are waiting for that day one to arrive. And the more prepared the health service can be for that, the better. And there's so many, you know like through the course of the last hour and a half, we've talked about some of the complexities for the person, for the health-care providers, for the organizations. This is a very new way of providing care within a health service. It's already extremely complex with so many players across private, public, aged care, tertiary... you know, there's a whole range of health care providers that there's a lot of avenues to consider. And it does take that long to put it in place. And it's much better to have something in place as prepared as possible, then to spend your 18 months of implementation after the laws available. And it's the people that are paying the price for that learning curve.

Steve Offner

So its a frustrating delay but a necessary one.

Susan Jury

Yeah. And it is like, you know, it's, you know, I think for many people, it's really tough waiting for that day dot and they are waiting for that day to then call the navigators on that day.

Gareth Wahl

Yeah, I think we're all really conscious that there's been a long, I mean, we ... people have talked about the (1995) Rights of the Terminally Ill Act in the Northern Territory. This has been... people have wanted this for a long period of time. And so we are all... all were very apprehensive. I can't even imagine what it must have been like to be in Victoria, before you had a big brother to copy, where the fear of making this go wrong, which then actually removes the access to care for everybody. You get this wrong once and... and I think we've all felt that weight from the onset of this, and I suspect that every other state will have the same degree, feel the same degree of weight on them of not wanting to get this wrong... to not, you know, prejudice other people going forward.

Steve Offner

Okay, thank you. Look, we are right on time. But there's a question in the Q&A about life insurance policies. And I guess related to that is what goes on the death certificate with somebody who's accessed and pursued VAD. Maybe one of the care navigators, Alice?

Alice Morison

Sure. So we do get questions about life insurance from time to time. If you have a terminal illness, I would encourage you to talk to your insurance provider and make sure you get access to that cash as soon as you possibly can, if you've been paying for it, and live it up! Because you know, it's an opportunity for you to use it in advance wherever you possibly can.

Now, legislation specifies in black and white, that voluntary assisted dying is not suicide, it likens it very much to a decision for a person to refuse another round of chemo or radio-therapy, or decide to refuse food or fluid. So in our state-based legislation, it is really clear, voluntary assisted dying is not suicide. In terms of the second part of that question, which... oh death certificates. Yeah. So our legislation is really clear that the death certificate cannot include voluntary assisted dying on it as a cause of death. So what you will see [on the death certificate] is the underlying condition that made a person eligible for access so... motor neurone disease, metastatic breast cancer, whatever made me eligible, will be what caused my death, because in order to access this, you are already dying from that condition.

Susan Jury

And that's the same in Victoria, on both counts. In Victoria, there's no overarching body for life insurance to make a position on whether they will pay out, but there's also no reason for them to know that someone's accessing voluntary assisted dying, and there's no reason for that to impact on a request for paying out of life insurance. And it's common, it's something that happens on a frequent basis.

Steve Offner

And one thing we heard recently, I think it was from WA, correct me if I'm wrong, but some people who were pursuing VAD were so proud of the fact that they were involved in voluntary assisted dying, they were actually determined to have voluntary assisted dying put on their death certificates. Is that possible? Legally not possible?

Susan Jury

It will always say the underlying illness.

Alice Morison

They can tell anyone they like though!

Steve Offner

Exactly. We are over time. So thank you. Closing observations. Does anyone have anything that they would like to add before we sign off?

Gareth Wahl

Call the Navigators! Call the Navigators. Their numbers will be put up, or if you type in your state's navigators, voluntary assisted dying, you'll find them in Google. They will walk with you.

Susan Jury

Thank you, Gareth. And I mean, I would say the same thing... there most likely will be care navigators in all of the states of Australia as these legislations are rolled out. Of course, we don't know that for sure, but I think we can expect them. And no matter... call them, your family's welcome to call them encourage your... if your doctor doesn't seem sure, get your doctor to call them or get your doctor's permission for the navigators to call the doctor. We will fill in those gaps and we'll help it make work for you.

Steve Offner

Alice, anything to add?

Alice Morison

No, it's just wonderful to have so many of you here tonight. And really thrilled to see the vigor with which you're approaching this and the questions that you're asking, because the more information you have, the better prepared you are. And the more likely it is that this will be a smoother journey for you or for someone that you care for. So thank you all so much for making the time to have a chat with us tonight.

Steve Offner

Yeah, and thank you. Look, just one thing about the care navigators and you know, Googling care navigators... some states are not going to call the care navigators, care navigators. I know, Queensland, for example, they're calling them VAD Support. But hopefully if you pop in care navigators, something will come up that will point you in the right direction.

Gareth Wahl

If you call the WA navigators they'll put you in touch as will the Victorians.

Susan Jury

Yeah, we all talk.

Steve Offner

Exactly. All right. Thank you so much. We are over time. Thank you to our wonderful panelists, Susan Alice and Gareth. Thank you to Renae from Go Gentle, who's been beaver away in the background here providing some tech support. I also want to thank the Groundswell Project, who organizes the Dying to Know Day events. So Dying to Know Day happens every year, this year, it's August 8. And there's usually a few weeks of events leading up to August 8, and this webinar was part of the wider Dying to Know Day events.

Thank you to everyone who registered and sent in questions. We tried to get to most of them. If there are any we missed, we will try to include some information in the literature we send out after this webinar. A reminder that this webinar was recorded, so if everything worked, we will be able to provide everyone who registered a copy of the recording, but the recording will also be publicly available on the Go Gentle Australia website.

And of course, thank you to everyone who tuned in tonight. We still have 200 listening and watching, so that's not too bad. Thank you for the time you've given up to hear this information. And just to reiterate, all people who registered will receive a recording of the webinar, a transcript, and links to any additional resources that were mentioned.

Now I mentioned a card with contact information that I'll put up now. We'll leave the webinar running for a few minutes, so if you've got a pen and paper handy, you can jot down that information. And I mentioned the QR codes. They should work as well. Keep in mind, not all states' voluntary assisted dying processes are up and running. So we've only provided information on the ones that are operating or are about to operate, so Tasmania and Queensland.

So again, thank you so much. We'll sign off now. I will put this last slide up. Feel free to stay online for as long as you need. Thank you.

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