# OPAN Webinar Transcript

**Title** What the New Aged Care Act will mean for you (series): End of life: your choices
**Recorded** 25/11/2025
**Video Link** opan.org.au/event/end-of-life/

## Panellists

- **Craig Gear** - CEO, Older Persons Advocacy Network (OPAN)
- **Dr Linda Swan** - CEO, Go Gentle Australia
- **Helen Callanan** - Founder & Director, Preparing the Way
- **Camilla Rowland** - CEO, Palliative Care Australia

## Webinar resources:

**OPAN:**

- Collection of resources explained in plain language
  OPAN's new aged care act resources
- Self Advocacy Toolkit - Advance Care Planning
  Self advocacy toolkit

**Other links**

- Palliative Care Australia
  Resources & downloads, available in multiple languages
  Discussion starters
- Go Gentle Australia
  Information & resources around Voluntary Assisted Dying
- Advance Care Planning Australia
  Information, resources, multiple languages
- Preparing the Way
  Information on doulas, including links to finding doulas
- Counselling support services
  Lifeline
  Beyond Blue
  13YARN

**Department of Health, Disability & Ageing**

- Learn about the new Aged Care Act
  New Aged Care Act

**Aged Care Quality & Safety Commission**

- Statement of Rights
  Statement of Rights - Fact sheet
- Strengthened Quality Standards
  Information & links
- Raising a complaint:
  Raising a concern or complaint - Fact sheet

[Announcer]

Across Australia, there's a network of independent, not-for-profit organisations giving a voice to older people at every stage of their aged care journey. Nationally, these organisations come together as members of OPAN, the Older Persons Advocacy Network.

Whether you or a person you care for is seeking aged care services or is receiving aged care services at home or living in residential aged care, our network of advocates are here to help you. Understand your rights. Resolve any issues you may be having with your provider. Help you express your needs and concerns. And we can help you access services you are entitled to.

Plus, our support is free and confidential, and we're independent from both government and aged care providers, meaning we're on your side. Nationally, we also raise awareness of aged care issues, taking your voice all the way to government.

To be put through to your local, state or territory aged care advocacy service, call OPAN's National Support Line on 1800 700 600, or for more

information, visit opan.org.au. OPAN, the Older Persons Advocacy Network.

[Disclaimer]

This webinar discusses end-of-life care, including voluntary assisted dying. We recognise these topics can be emotionally challenging. Please feel free to pause, step away, or stop watching at any time. If you become distressed or need support, consider reaching out to one of the support organisations listed at the top of this transcript.

[Craig Gear]

Hello, my name is Craig Gear, and I'm the CEO of the Older Persons Advocacy Network, or also known as OPAN for short. Thank you for joining us for today's webinar, covering the sensitive and important topic of "End of life: your choices," which is part of OPAN's "What the new Aged Care Act means for you" series.

[Opener Graphic]

But before we begin, in the spirit of reconciliation, the Older Persons Advocacy Network acknowledges the traditional custodians of country throughout Australia and their connections to land, sea, and community. And we acknowledge the Gadigal from the Eora Nation on whose lands we are on today.

We pay our respects to elders, past and present, and we extend that respect to all Aboriginal and Torres Strait Islander people joining us.

End of life. Eventually, it comes to us all, but it's not a topic that we all feel comfortable talking about. Well, that is exactly what we're talking about today.

But before we move on, I also actually wanna acknowledge that the conversations about the end of life, it can bring up a range of feelings, memories, or concerns.
And today, we'll also be talking about voluntary assisted dying, also known as VAD, which is now legal in the ACT and all states, and for those who are nearing the end of life who meet certain criteria. We know that some in the community don't support voluntary assisted dying, and we respect that. We at OPAN respect all perspectives, and most importantly, the individual's choice on this matter.

Given the nature of our discussion today, please take care of yourself as you watch or participate in today's webinar. And look, if at any time you need a moment to pause or to step away, just please do so.

Now, although this topic can be difficult, planning for and talking about end of life can also bring comfort, clarity, and peace. And not only for older people approaching their end of life, but also for their families and carers, and really, the communities who support them.

Open conversations and proactive planning helps to ensure that a person's wishes are known, that they're respected, and that they're upheld, really giving them greater dignity and control.

Speaking of open conversations, let's hear from some older people who we asked about this topic.

[Video]

[Dennis Frost - NOPRG Member]
Well, when I think about end of life, having some choice and control over my final days is very important.

[Jan Schaffarz - NOPRG Member]
Being cared for as a whole person, having my wishes played out.

[Judith Lovell - NOPRG Member]
Having a spiritual person there that's consistent with my faith background.

[Gwenda Darling - NOPRG Member]
It needs to be done my way, pain-free, preferably when I decide. That's why I got a tattoo, "Do not resuscitate." And I hope people respect that.

[Dennis Frost - NOPRG Member]
I must admit, now I would like to be able to have a final goodbye with my grandson.

[Danijela Hlis - NOPRG Member]
Personally. I'm not afraid of dying, but I'm extremely scared of suffering, prolonged suffering and neglect, and abuse that I see happening all the time.

[Rosemary Seam - NOPRG Member]

I imagine it would be not having pain and not having to worry about anything, and just drifting off into the sunset sort of thing. I mean I haven't got much idea.

[Craig Gear]

That's just a small example showing the varying and individual nature of what's seen as important to older people when discussing end of life care. And you'll be hearing more perspectives from those members of the OPAN's National Older Persons Reference Group throughout the webinar today.

So it's now just been over three weeks since the new Aged Care Act came into effect on the 1st of November. And while in our view, the new act is not perfect. It does importantly place a stronger emphasis on ensuring the dignity and rights of older people are upheld, including the right to access palliative and end-of-life care that supports dignity, comfort, and choice.

But what does this mean in practise? Well, that's exactly what we're going to look at in today's webinar. Coming up. First, we'll look at what it means to have an end-of-life journey and how this is more than just clinical care. We'll then discuss the key changes under the new act and how it recognises the right and quality in this space. Then we'll cover best practise across what good support looks like, planning ahead, considering people of diverse needs and backgrounds, plus grief and bereavement support. We'll discuss the topic of voluntary assisted dying, including around capacity. And finally, we'll cover practical steps to help with talking about the topic, plus where you can find supports and further information, including on how to go about advance care

planning. And of course, we'd also like to hear from you as we wrap up with our live Q&A.

Now, to help us unpack all this, I would like to introduce today's expert panel. Firstly, joining us remotely is Camilla Rowland, CEO of Palliative Care Australia, and national leadership on quality palliative care and resources for individual carers and providers. Thanks for joining us, Camilla.

[Camilla Rowland]

Thanks.

And here in the studio with me is Dr. Linda Swan, CEO of Go Gentle Australia, who advocates for consistent, compassionate approaches to end-of-life decision-making across Australia, including access to voluntary assisted dying, or VAD, where it is legal. Welcome, Linda.

[Dr Linda Swan]

Great. Thanks Craig.

[Craig Gear]

And also joining us here in the studio is Helen Callanan, founder and director of Preparing the Way, an organisation that provides education and training for end-of-life doulas. These doulas support people and families to prepare emotionally and practically for death, dying, and bereavement. Thank you for joining us, Helen.

[Helen Callanan]

Thank you, Craig.

[Craig Gear]

And of course, if you register to view this webinar, you'll receive a follow-up email with all the resource links, including key slides that we show you today. Finally, if you need any further support or having any issues with your government-funded aged care services, OPAN's network member advocates, they're here to support you and provide free, independent, and confidential support. You can access them by calling the aged care advocacy line on 1800-700-600.

[Craig Gear]

Right, let's get started by, first, all getting a better understanding of the end-of-life journey, including some of the terms that we'll be using today. Camilla, I might start with you. Can you help define what we mean by palliative care and end-of-life care, and what's the difference here?

[Camilla Rowland]

So, palliative care is a care model. It's also contains a medical model of care within it, which is an internationally recognised model. And it is about symptom control, pain management, social, emotional, and spiritual support.

So it's a very holistic model of care. And that would normally take place, the best practise would be from time of diagnosis, when it's known that an illness cannot be cured, then palliative care would be introduced at that time. So it could be years in advance of death.

It might be months, but it's from that time of diagnosis. End-of-life care is more about those last weeks and months before you die, and that more intensive care that's provided in that time.

[Craig Gear]

Yeah, I think it's important because I think we make the assumption that palliative care is just at that last, and knowing that people can access that for a number of years is really important. So, thanks Camilla.

Helen, your organisation provides holistic supports across the entire end-of-life journey through a role called a doula. You spoke to OPAN earlier about a 10-steps model. Can you also explain that and maybe briefly about what a doula does?

[Helen Callanan]

Yeah, thanks Craig. So we teach inside and practise inside of a 10-step model of 10 stages of life, and this was created by Natural Grace Holistic Funeral. And what it's talking about there is that as a person is advancing in age or living with a diagnosis, dying from a diagnosis, they're going through a number of different stages, as are the people that care for them and with them.

And so there's a lot of change going on all the time. Things are progressing. There's new teams, some leave. So who is it that can actually authentically accompany a person on their entire journey through those 10 stages? And doula is one of the unique professional roles that can actually do that.

So we are a non-clinical, non-medical. So as Camilla was sharing about the medical side of things, so that's what we don't do. We don't share. We don't take care of people medically. We can provide all of those other elements of care, holistic nature.
So, relational care. Actually, cultural support, emotional, spiritual, like all realms of support. And we provide education and resources for people. So we're accompanying them and the people close to them on that entire journey. And that's basically what a doula does.

[Craig Gear]

Yeah. Thanks, Helen. I love that the first step in that model is about living well as well.

[Helen Callanan]

Yeah, well, that's when, mostly, we should be planning then, right? When we're well and don't need that emergency care and stuff.

[Craig Gear]

Linda, we'll be talking about voluntary assisted dying a little bit later on. I just do point people that we have that 10-step plan up there, on there.

Voluntary assisted dying. Legally, it's only fairly recently been introduced across all states, and I think at only this month in the ACT.

Can you give us a quick lay of the land of what's happening and where things are currently at?

[Dr Linda Swan]

So one of our biggest issues with voluntary assisted dying is that there is a lack of awareness because, actually, it's been running in Victoria for six years.

[Craig Gear]

Oh, so it's not that short.

[Dr Linda Swan]

So in some instances, it's a mature services, but for places like the ACT, it's just started. So we've got a wealth of experience around the country. Some people are just learning about it and some people have really had it as part of end-of-life care for many years.

But in essence, it's just a choice. It's a choice available for people who are eligible. And in order to be eligible, you need to be dying and suffering. You also have to demonstrate that you have full capacity, so you can be clear that you're making this decision freely, of your own will, and that you have the capacity to understand that you're essentially asking someone to help end your life.

It's a very, very serious decision. But for those people who get to the end of their life and they don't want to live anymore, they've got a terminal illness, they're suffering, and they're looking for someone to help them die, that's what voluntary assisted dying can do.

[Craig Gear]

Right. Thank you, Linda. Well, as mentioned earlier, the New Aged Care Act is now in effect. Camilla, I'll throw to you on this.

What are the key changes under the new Aged Care Act in relation to this topic? And how does it strengthen older people's rights in this space, both for those who might be living at home or those that are living in residential aged care?

[Camilla Rowland]

So anyone who's accessing government-funded aged care services has a right to have palliative care provided, and that means that providers have to set up systems and processes, and ensure their staff are trained to deliver good quality palliative care.

And Helen referred very well earlier to living well. Palliative care is all about remaining in a situation where you can have quality of life until you die. And so they need to ensure that they've got planning in place and care in place, both at home or in aged care facilities to ensure that happens.

So the rights are that people can expect that and people can expect to have conversations, and things change. So what they may believe and

feel one month may change another month, or another few weeks later. It is an iterative conversation. It's a living document advance care plans, or a care plan, in fact.

And so we can expect that aged care providers will ensure that they enact specific changes to make all those things under 5.7 of the outcomes in the Aged Care Act.

[Craig Gear]

Right. Look, there's a lot there. And I know that there is an advanced end-of-life pathway, but also I love that it's now enshrined in rights about someone's right to good palliative care and end-of-life care.

Linda, is voluntary assisted dying, is that mentioned specifically in the act? And what are people's rights when it comes to that?

[Dr Linda Swan]

Unfortunately, it's not specifically mentioned. We would've liked it to be mentioned so it's really clear for people that when they're in an aged care facility, they have a right to make a choice to access voluntary assisted dying. But it it is there in the principles of the act, which is about people in aged care facility have a right to be able to access the same types of health services that they would get in their home because their aged care facility is their home.

[Craig Gear]

Yes, I think it's important that it covers you at home, but also in a residential aged care home as well, because it is someone's home.

[Dr Linda Swan]

Yes, that's right. So the difference with voluntary assisted dying is that some people have a conscientious objection to being involved in the care, which is perfectly reasonable.

If people don't believe in it being the right thing for them, they don't have to be involved. But in an aged care facility, if the facility decides not to deliver assisted dying services themselves, they still have a need, or under the act, they should allow access for people to come in, speak to the person, and help them facilitate voluntary assisted dying.

[Craig Gear]

Thank you, Linda. I think that's really important. Okay, let's take a look at best practise for support in both palliative care and end-of-life care. But before we do, let's have a look at this.

[Gwenda Darling - NOPRG Member]
Good end-of-life care should look like services delivered to keep the person who's passing pain-free, allowing family to be there and support them, and for them to be able to be treated in culturally appropriate ways in their own home.

[Jan Schaffarz - NOPRG Member]

A good end of life is everyone's on board. It's a peaceful environment. Everything's been explained to the patient and the family about what they might see and hear. There might be, you know, noisy breathing.

[Gwenda Darling - NOPRG Member]
Good palliative care should be 24/7, including weekends.

[Rosemary Seam - NOPRG Member]
But the palliative care is sort of making someone comfortable, making sure they're at peace with themselves, if possible. You're not suffering, you're not in pain as far as it's possible. And you don't want that agony prolonged needlessly for anybody.

[Jan Schaffarz - NOPRG Member]
You should be able to have a space to do, you know, your special rituals or a place for family to be able to come and do what they need to do.

[Craig Gear]

Look, a big thank you to everyone who shared their perspectives. There's a lot to unpack there.

Camilla, can you talk to us about what is best practise here and what can people expect from providers to ensure their wishes and preferences, that they're actually really, truly respected?

[Camilla Rowland]

Yeah, so best practise, I would say that an assessment should be done with the person, with whoever they want to have attend with them, if

that's family or the people closest to them, to really talk about what gives them quality of life and what's important to them.

As you just saw from those videos, everybody has a different idea about what is important to them. But I will say that for most people, high up on their list is often about pain management. Most people do not want to be in pain.

And so an essential part of that assessment is looking at what sort of ideas do people have about what they want in terms of relief from pain and other physical symptoms, planning for the future medical treatment decisions, and what are your goals of your care?
What will make you comfortable and actually give you quality of life? And that obviously is addressed through that emotional, social, and spiritual components as well.

So it's often helpful for the people in someone's life to come together with them and all be on the same page in terms of understanding where that person's at with their illness and what do they want to have happen now, next week, in the weeks and months to come. And that will change, as I was saying earlier, it's an iterative conversation.

It's not just one plan that happens when someone enters an aged care facility or has aged care providers at home for the first time. It's a living document. And that can include referrals to respite as well. It might be thinking about where do people want to die as well. It may not be in that aged care facility or at home. It may be in a hospital or it may be in a hospice.

[Craig Gear]

Yeah. Thanks, Camilla. Helen, we've been hearing about how planning plays a really important role in this space. When it comes to an older person and their care network, what do people need to be aware of and how do they plan ahead?

[Helen Callanan]

Mm. I think, honestly, to do planning ahead of when it's needed is the greatest gift to yourself, but also the people who care about you. As doulas, we often talk about plan A and plan B. So what are your preferences? What's important to you?
Do you even know what your wishes are? We actually use the palliative care document, the discussion starters, as one of the tools that's available to get people talking.

And I think that's where it has to start, it's conversations. And maybe people could use something like seeing an event today. "I saw this event, it made me think about things." It's conversations.

It's making notes about things. It's writing things down. And what if you can't have your first round of preferences. Right? What if we can't achieve those? What if your primary care people get sick? What's your plan B? Let's talk about it now before it's needed so that we're not dealing with a crisis, in a situation.

The other thing too, planning's got so many facets to it. The difference between an advance care plan and an advance care directive. One is a legal document. The other is, what if you need long-term care?

I lived with my mom for seven years as she journeyed dementia. And as a result of that, I know the goalposts keep shifting. And Camilla made a great point about how it has to be a living document.

It changes, we change, the needs change, the goals change. So how do we make document? But it's about, talk about it, document it ahead of time if you possibly can, and review, review, review.

[Craig Gear]

Yeah, it's so important about having those conversations. And you mentioned there about advance care planning, and we'll be sharing some more resources on that a little later.

Camilla, back to you. If someone has been diagnosed with an illness that may result in cognitive impairment and a reduced capacity over time, such as dementia, what's your advice on how they might approach end-of-life planning?

[Camilla Rowland]

Yeah, it's really important that when people are diagnosed with dementia, they start to have those conversations earlier so that their loved ones or their friends, whoever's close to them, has a really clear picture of what their wishes are. So in a sense, they can become their advocate as time goes on.

The dilemma we always have is that people do change their minds. And someone with dementia could easily change their minds some months,

some weeks down the track. It is a very tricky situation to understand what someone's current wishes are.

So going back to what they think of their foundational needs and their foundational desires is really critical when starting to think about the planning.

Coming back to what Helen also mentioned around plan A and plan B, you may think that you are going to be the carer for someone with dementia right up until the end, but the reality sometimes are that there's an incredible amount of physical and mental work, and care that's required. And it may not be possible for that person to remain at home.

So, although they may say their plan A is that they'd like to die at home and be cared for at home the entire journey, it may not always be practically possible unless there's a really good network of support. Because caring for someone with a cognitive decline, and that could be dementia, is often months, if not years, in the making. And you have to think about the stress levels and the health needs of the carer and the family that's involved.

[Craig Gear]

Yeah, I mean, carers are so vital to this conversation as well, and the support that need to be there for them. Helen, when it comes to people with diverse backgrounds or diverse needs, or even those who might be from regional remote areas, what things should be considered here?

[Helen Callanan]

I think, look, everybody's an individual. And even people in the same family or the same community, or the same culture, they're still individuals. So there's a lot about talking to people, asking questions, doing a lot of listening, a lot of documenting.

We also have to take into account people's cultural and spiritual needs. It's not just emotional, it's not just practical. There's so many layers to whole person care. And so we really want to support people by asking a lot of questions. What is your tradition? Who is important to you? Where do you want things to happen? How do you want things to happen? And then if you go regional and remote, and I came from the bush, so this is pertinent to me. And I understand you've often got a lot of distance in play. You've often got less services.

Because palliative care can be a bit of a postcode lottery in reality, whilst they're doing great work. So that puts a lot of stress back on families, but also networks in the community.

But I think it's really important that people are talking to people asking, being active in what resources are actually out there. How do I find out what is available in my community? Who can I talk to? And really, doing sort of the research on that. Because we've gotta be aware of things like people's customs.

What's your belief system around grief, around talking about death and dying. For some people it's, "I don't talk about it." Other people are like, "Yes, we will." So what are people's culture around the handling of the body after death? Do you get what I'm saying? There's so many layers.

And I think that's the biggest thing, is never assume anything. And we can't try and create a one-size-fits-all. And that's where we can get a bit cookie cutter in the conventional care system sometimes. It's gotta go back to individual, individual, individual, as the people in your reference group have been saying.

[Craig Gear]

Yeah, it's so nuanced, isn't it?

And you mentioned it there, but I really would like to talk about grief and bereavement now. Because as good care, it really does continue beyond the time when someone dies. And it might even start, I think, beforehand. And I've heard a little bit about anticipatory grief as well.

Before we come to that though, let's hear a bit more from OPAN's Older Persons Reference Group on this topic.

[Gwenda Darling - NOPRG Member]
Good palliative care doesn't stop at the actual passing of the person, when the person stops breathing and its soul leaves its body, it continues and supports the family, the loved ones, the carers. And that support needs to be going on for some time after all the formalities are completed.

[Judith Covell - NOPRG Member]
My older sister, she died in residential aged care. I mean, she was aware that she was dying some months before, and so she actually had a wake for herself. She had a party months before, and she invited all the family and a couple of friends. And we actually had an opportunity to

say things to her publicly about how much we loved her and how we'd valued her. And I think that was really such a gift that she gave all of us.

[Craig Gear]

Oh, thank you Gwenda and thank you Judith for your perspective there.

Camilla, when it comes to grief and bereavement, as Judith mentioned in the video, this can start before someone dies. What are older people's rights here and what are some examples of good practise in this space?

[Camilla Rowland]

Yes, very well picked up, because anticipatory grief, as someone said earlier, is very present right from time of diagnosis. And even just moving house or moving into an aged care facility, or the change of your circumstances can create that grief reaction.

So aged care providers need to be able to provide that grief and bereavement support. And there's lots of tools and resources available around this. The early end-of-life directions in aged care were also known as ELDAC, is a great programme with excellent resources for aged care providers around anticipatory grief, how to build up the skills of your aged care workforce, how to build up the knowledge of the other residents in aged care facilities to support each other.

But we do have a barrier and a challenge. And the challenge is this, if you're in an aged care facility, or even if you're at home, and you have people coming in to provide that support and care up until death, many services are not funded to continue providing that care post-death.

So once the funeral is over or the event has occurred, not many palliative care services even have its sufficient funding to provide comprehensive follow-up.

The good model is to provide care follow-up for at least two years. But we know, in terms of postcode lottery and funding availability, that the reality of being able to provide that care follow-up for family members post-death is really limited. And it'll be interesting to see what aged care providers are able to do in terms of what they can provide post-death.

[Craig Gear]

Yeah, 'cause it doesn't end. And I think I remember that people talk about, there's a community of people in residential aged care who get affected by this as well.

Thanks, Camilla. In the lead-up to this webinar, we've received a lot of questions and shared perspectives from older people expressing their concern around not having the choice to end their life should they be suffering. And this leads us to the sensitive topic of voluntary assisted dying.

Now we're aware that this topic may prove confronting for some people, but at the same time, it's really important to others. Before we move on, let's hear a bit more from OPAN's Reference Group members.

[Danijela Hlis - NOPRG Member]
I have seen people dying for 18 days on very little morphine, and with no food and drink just because they call that a natural way of dying.

And I witness people who are over to mother tongue and keep on asking to be let go, or at least to have more painkillers, and care staff doesn't understand them.

It makes no sense to me that doctors say they must save lives, not take lives. This is not about taking a good life. It is about helping to end a very painful and prolonged suffering. There's a huge difference in that.

[Rosemary Seam - NOPRG Member]
The people I have spoken to feel very concerned that they should have the choice to opt for voluntary assisted dying if it's needed. We feel it's a matter of our human rights. If it's the law, it shouldn't be barred to people in residential aged care just because of their situation.

[Danijela Hlis - NOPRG Member]
I want to decide if and when I want to end the suffering that I may experience.

[Craig Gear]

Look, thank you to Rosemary and Danijela for your views here.

Linda, for some older people having the choice to end suffering, should it come, that's really important to them. What is involved and what are the criteria to access voluntary assisted dying, and how do rights come into play here?

[Dr Linda Swan]

So voluntary assisted dying is dictated by law in all jurisdictions. So it does differ a little bit from different states, depending on where you live. The easiest place to go and understand things in detail would be to go and have a look on our website, 'cause we've got some fantastic tools.

You can click on a map of Australia and you can see if you're from Queensland. These are the rules, and this-

[Craig Gear]

Because they're state and territory laws that guide this. Yes.

[Craig Gear]

There is slight differences between the different jurisdictions, but there is an Australian model. So there's a lot of similarities across all jurisdictions.

So in the Australian model is, that you have to have two independent doctors verify that you are eligible. And to be eligible, you have to have, essentially, a terminal illness. It must be advanced, progressive, and causing you intolerable suffering. So, dying and suffering. You've gotta be close to the end of life.

[Craig Gear]

Yeah.

[Dr Linda Swan]

You've also gotta be over 18. You have to have full capacity to make the decision and the doctors have to verify that you're not being coerced. No one else is pushing you into this. And the process is designed to be long. So you therefore demonstrate over a long period of time, weeks to months, that this is an enduring request that you have.

You haven't just suddenly made up your mind. You've gotta make three different requests. So it's really carefully designed to make sure that the people that are accessing these laws are dying, they're near the end of their life, they're suffering, and they are making this choice freely.

[Craig Gear]

It's a free choice. Yeah. Look, thanks Linda. But before we move on, I do wanna make it clear that if someone is choosing the VAD pathway, that does not mean that they can no longer access palliative care and other supports. Camilla, come to you. Have you got anything to add on that quickly?

[Camilla Rowland]

Yeah, it's very important that people understand that they're not mutually exclusive. People can have both palliative care and voluntary assisted dying. And in fact, it's quite common for those people who have selected voluntary assisted dying that they actually receive palliative care right up until they press the button, so to speak. And that's our position. It's about individual choice. And you can have both or either.

[Craig Gear]

And I've actually heard of people who've gone through the process of approval and then not used voluntary assisted dying, and continued on the palliative care pathway. I think that's really important.

[Dr Linda Swan]

Yeah, about 30% of people. So, quite a lot of people go through the process. They're approved. But just the process of being approved gives them such relief and such strength that they decide not to use it.

[Craig Gear]

Yeah, and working alongside palliative care as well. Now when we asked members of OPAN's National Older Persons Reference Group questions about palliative care and end of life, the topic of voluntary assisted dying and capacity came up multiple times. It's a sensitive topic, and some of the content that we had to talk about, it may be confronting, but it is really important for people to be able to share their perspectives. Let's take a look.

[Gwenda Darling - NOPRG Member]
What started me thinking about it was my dementia diagnosis initially. And then I kept being told, "No, you are too healthy and you can live in quite a demented state for many years." So it's not actually the venture that is stopping me that's getting voluntary assisted dying, it's actually that my body is too healthy and my capacity is still there. But when I will have less than six months to live, I won't have capacity, and they won't honour what I have written down.

[Judith Covell - NOPRG Member]

There's a lot of older people who think that if they write it into their advance health directive, that if they have dementia, that they can utilise VAD, and of course, they can't. And I'm wondering about when that realisation starts to go through the older population, what effect that's going to have?

[Dennis Frost - NOPRG Member]
Yeah, with a lot of other people with similar diagnosis as we've had conversations around how they see the end of life for themselves. One thing I'm really aware of is the high, for want of a better word, attempted suicide rate amongst people with similar diagnosis.

[Danijela Hlis - NOPRG Member]
If I have to go to Switzerland to do it my way, to end my suffering, should there be needed, I will have to do that because I don't believe we have enough flexibility and choices in Australia.

[Craig Gear]

Linda, I know this is a really tough one. What are the rules and the laws when it comes to voluntary assisted dying and capacity? How do we navigate this?

[Dr Linda Swan]

So one of the principle, the foundation rules around assisted dying is that you need to have capacity throughout the process. So the complication is that for many people towards the end stage of dementia, you lose capacity.

So under the current laws, you can no longer access voluntary assisted dying. I think the frustration that we hear so commonly from our community events as well is that people don't want that outcome.

They've seen loved ones. They've heard about what happens to people at the end of life with dementia and they don't want that outcome for themselves, so they're frustrated by the current laws.

But the current laws have been very carefully designed to try and reassure everybody in the community that only people that have full capacity to make this decision themselves can get access.

So at the moment, what we really need to do is to look at how can we explore the evidence base to think about different ways that we might create a type of end-of-life care model that might need the needs of people with dementia. But we are a long way from answering that question yet. There's a lot of research that needs to happen.

[Craig Gear]

Yeah, and it makes sure that people living with dementia or dying with dementia are also getting access to really good palliative care as well. Thanks, Linda.

Oh, well, we're not far away from our live Q&A, and thank you to those who have sent in questions. But just before we get to those, let's first look at some practical steps and supports that are available, including when it comes to talking about it.

[Dennis Frost - NOPRG Member]

Well, talking about planning for end of life can be very difficult with family.

[Judith Covell - NOPRG Member]
Yeah, I mean, it's a bit of a dilemma that I have at the moment. I'm not quite sure how to address that, to be honest.

[Rosemary Seam - NOPRG Member]
When you're having a social gathering with your family, it's not the sort of thing you can really bring up, you know, in the middle of Christmas dinner or whatever.

[Judith Covell - NOPRG Member]
Family can get quite emotional and have their own ideas about how they'd like things to go.

[Rosemary Seam - NOPRG Member]
I haven't spoken with my family or anyone close, but I have discussed it with other residents in my residential aged care facility.

[Judith Covell - NOPRG Member]
I do find that I'm able to talk with friends, with older friends, a lot more easily. The younger generations actually resist, sometimes, talking about it.

[Judith Covell - NOPRG Member]
I think it comes up when, you know, perhaps there's a death in the family, and then that opens up the conversation for what we all would like.

[Rosemary Seam - NOPRG Member]

If I did have a terminal illness, then I'm sure my family would be willing to discuss my options with me.

[Judith Covell - NOPRG Member]
Sometimes it's easier to talk to a neutral person, not family initially. So it might be easier for the older person to start the conversation with a neutral person, you know, a health professional. You start the conversation and get your choices about what you want. And then a health professional could be involved with having a sit down with the family and going through it.

[Dennis Frost - NOPRG Member]
In a more clinical environment, it can be easy to discuss to some extent, but also can be more difficult in having a really meaningful conversation that way.

[Danijela Hlis - NOPRG Member]
I have expressed my views when I'm asked, but I would never, never impose my beliefs on anybody who's not interested in them.

[Gwenda Darling - NOPRG Member]
We need to start talking about, not only what we want for our end-of-life care plan, or for our living care plan, how we want to live at the end of life, but we also need to be talking about what we expect from family members. I know a lot of families don't want to discuss death. They have this fantasy we are gonna go on forever because it's their fear, their anticipatory grief. But we need to be the strong ones and say this is a reality, this is what we want, and this is what we need you to do. And if families aren't missing, I suggest you write it in a letter, give a copy of the letter to the GP, write a letter to each of your children. Do you want your

dog brought beside you? Do you want to be taken to a hospital so you don't leave spirits? Or do you definitely not wanna be institutionalised? Do you wanna go home and die on country? We need to be really clear about that as individuals. It's our responsibility to ensure our family, our medical team, our carers all know. It starts with us, ends with us.

[Craig Gear]

Look a massive personal thank you to our National Older Persons Reference Group members who've spoken to us. Danijela, Dennis, Gwenda, Jan, Judith, Rosemary, thank you so much for sharing your perspectives today.

Yes, talking about it can be challenging. Camilla, I know you've got a great discussion starter area on your website. Can you take us through that and share more about it, and then any tips that you might have?

[Camilla Rowland]

Yeah, it's interesting how all the older people that were just being interviewed were saying it was difficult to have the conversations. And we have a campaign every year about raising awareness about what palliative care is and talking about death and dying.

What we do know from research is that the younger generations are more open to talking about death and dying. And I think since COVID and the introduction of voluntary assisted dying, it's becoming more part of our everyday conversation.

But often say in those conversation starters, talk about while you are healthy, while you can think clearly, what do you think is going to happen in your journey, and what would you like to have happen in terms of your care?

And it might even be about things like what you want to happen with your animals, your pets, where you want to be. So as Gwenda quite rightly said, if you feel you can't talk to somebody about it, document your wishes and give those to somebody who's close to you that you can then start that conversation with.

[Craig Gear]

Yeah, so I think you've got some stuff on your website here. Step us through some of this and some of these conversations started part.

[Camilla Rowland]

Yeah, in that booklet, you've actually got some questions and answer space, and just things that will prompt those conversations about, for example, with pets.

What's important to me about what happens with my pets and the way they looked after? What's important about the way my family is supported, not just myself, what's important to me? Having someone with me when making health decisions, having an advocate. It doesn't always have to be a family member.

Some people don't have close families nearby. It might be a friend. It might be a death doula. It might be somebody else that can guide you.

So having someone that can advocate on your behalf for you when you're not feeling well is a great thing to have in place as well.

[Craig Gear]

Yeah, I love those little cards, which is like something you could start that conversation with.

Helen, do you have any tips for older people on about how they could start having these conversations and help people to talk about this? And where can people find out more information about what is a doula.

[Helen Callanan]

Sure. So I think one of the hardest things, as it's been said, is about starting the conversation. And I really support what Gwenda was saying is, you know, we've really gotta bring it to the table and express what our things. And one of the great ways that I've found to start the conversation is to start with me. So I've got this plan in place.

What do you think about that? Would you like that or would you not like that? Also, as I mentioned, using something like the discussion start or something like this webinar. I was at this great webinar. Oh, they said this, this, and this. What do you think about that? And documenting, you don't have to do it all in one go. Breaking it down.

Having those conversations is the critical piece. And I think that the other thing is, there are a lot of people out there that might relate to, "Oh, it doesn't matter, I'll be dead. I don't care. Do whatever you like." And I have one of those in my family.

So my strategy for that was, you know what, I am gonna make their plan. I'm gonna write everything down because I wanna be able to grieve and I wanna be able to be with them. I don't wanna be running around going, "Oh my god. What will we do now?"

[Craig Gear]

Yeah, there's a lot to plan there.

[Helen Callanan]

There really is. There's a lot and there's a lot of emotional, so we don't get to grieve.

[Craig Gear]

Yeah.

[Helen Callanan]

Right? So I made my own plan for this person, and I went to them, I said, "Well, here's what I've got planned." And they're like rolling their eyes looking at me. But I soon found out where I was wrong. They were like, "No, I don't want burial. I wanna be cremated. Oh great, thank you so much." Tick. You know? So it can be done that way too, but it's about talking about it, documenting it, and then sharing that with the people close to you. Family, your GP, My Health Record, all of those places.

And you're right. There's so many places that we can now get support. It might be an end-of-life doula, it might be your GP. Might be one of OPAN people. I know you've got really great advocacy groups. It can be the GP if you can't start with your direct family or if you don't have someone. So it's just, have the conversations, ask the questions, document them and share them.

[Craig Gear]

Yeah, and even though it's uncomfortable with that two-way conversation.

[Helen Callanan]

Yeah, yeah.

[Craig Gear]

Yeah. Linda-

[Helen Callanan]

And sorry, you did ask me, sorry, about share-

[Craig Gear]

Oh, yeah.

[Craig Gear]

Sorry. So that's our website there. Thank you. And we have a find a doula.

[Craig Gear]

Yep.

[Helen Callanan]

One of the other organisations that I recommend strongly is organisation Doula Connections. They actually specialise in placing doulas, whether it's for planning or for care, both in homes as also in residential facilities, all of that.

And then there's also the end-of-life doula directory that has a number of people on their train by different trainers. But it's important, you know, Palliative Care Australia created a great end-of-life doula fact sheet. And in that, they've got some questions, and you can find that on their site.

They've got questions there about what you should ask if you're interviewing a doula. Do they have insurance? Do they have a code of conduct? Things like that. Because you wanna have a relationship of trust. And so that's an important thing to follow as well.

[Craig Gear]

Yeah.

[Helen Callanan]

Some places to start.

[Craig Gear]

Linda, can you share about where we'd go to look for more information about voluntary assisted dying, even it's in different states and territories?

[Dr Linda Swan]

It can sound a bit confusing and overwhelming, but there are two really simple places to go and get information. One is from our website. So if you go to the Go Gentle Australia website, there's a whole wealth of information about the different laws, but also simple examples of patient stories.

There's Q&As. There's resources there for people in lots of different medias. You can watch little video clips. You can read stories. The other place is a care navigator service, which has been set up in every jurisdiction. It's a telephone call away, and they are people who are trained to understand and communicate the process for people that are thinking about going through voluntary assisted dying.

So have a look at our website and you'll find there information about the care navigator sites. And then if you want more detail, call the care navigators, and they can walk you through the whole process.

[Helen Callanan]

They're so great, the care navigators, I've worked with them a lot. They're great.

[Craig Gear]

Fantastic. Finally, another fantastic resource is Advance Care Planning Australia and their website, where you'll find a range of resources on creating advance care directives, plus information on capacity, substitute decision-making, and including resources that will be available in multiple languages. And you can see their details on your screen now.

Also, on the OPAN website, we have a dedicated area which covers advance care planning as part of OPAN's self-advocacy toolkit. And this includes a webinar just like this one, which discusses such topics as, what is advance care planning, when and how should I create an advance care directive, and much, much more. And you can find this by heading to opan.org.au/toolkit.

Right. Let's now move along to our live Q&A. Thank you to everyone who has submitted questions. And you may notice some of those are being archived as they come through, but rest assured that we are receiving them all and we are working hard behind the scenes to collate them all and feed them through to my iPad so that we can answer as many of them possible.

Panellists, lots of questions. So I'm gonna have to keep you to short answers as we go here, but let's get underway.

First one is for Camilla, and it's from Janet. How is a dying person living alone and without family or support networks supposed to benefit from the new palliative care options in the new Aged Care Act?

[Camilla Rowland]

Yeah, so for those of you who don't know what the options are, the end-of-life pathway enables people who are at home to have three to four months of an additional number of service hours.

But it would not be sufficient for 24 hours a day care. It's really geared up towards providing a certain amount of support each day, but assumes that somebody will have a network that comes in to assist as well.

So the reality is, that if you are on your own completely, the likelihood of you being able to die at home with full 24 hours a day care is not going to be realistic unless you've got money to pay for that privately to top up.

[Craig Gear]

Yeah, so family are gonna be important in that as well.

[Camilla Rowland]

Or friends.

[Craig Gear]

Linda. Or friends. Yeah. Linda, Alice has got a question, how far in advance can I ask for voluntary assisted dying?

[Dr Linda Swan]

Well, there's no specific rules about how quickly you need to apply, but you'll need to be eligible. So there's a process that you go through and different jurisdictions have different timeframes, but it's generally between six and 12 months from death.

So if you'll speak to your doctor about voluntary assisted dying three years before you're likely to die, you are probably not gonna pass the eligibility test. But it's a really useful conversation. We've been talking about starting early, planning early. It's a really useful conversation to have with your family and your carers as soon as you start thinking about your end of life.

[Craig Gear]

What you wanted to know.

[Dr Linda Swan]

So they know what you want.

[Craig Gear]

Yeah.

[Dr Linda Swan]

And then, when you get closer to the end of your life, certainly, 18, 12 months out, it's definitely time to have some more in-depth conversations with your health professionals.

[Craig Gear]

Right. Helen, question from Mary. If I don't have a family member or close friend who would be able to make informed choices for me financially, medically towards the end of life, who or where can I go to for assistance in this area?

[Helen Callanan]

Great question. And we're seeing a lot more of that now where people really are feeling very isolated and alone. So there's a number of things. So if you can't get someone to do that for you, pretty much every state has a public trustee, public guardians.

There's also things like OPANs advocacy group. There are also maybe GPs and social workers can help resource people with that. End-of-life doulas can come into that space as well. We don't make any decisions.

[Craig Gear]

Yeah.

[Helen Callanan]

We don't do that. But we can help people access what support there is out there in community. There are legal services out there that help as well. So there's a number of different things that people can access.

[Craig Gear]

Right. Camilla, how will families and substitute decision-makers stay involved in planning and communication when an older person's condition becomes terminal or changes quickly? That's something that David would like to know.

[Camilla Rowland]

Yeah, so I'm not quite sure whether David's meaning at home or in an aged care facility, but let's tackle both. If they're in an aged care facility, the aged care provider has to ensure that the family that the family that's identified in that person's care plan is notified as things change.

And clearly, also the family or the friends involved, need to be visiting regularly. But we would be assuming also that if that person's got some medical decline happening, that a palliative care service or a GP, or a geriatrician is involved as well and can actually prepare the family, prepare the person with where things are coming, where they're at.

So in those last weeks and days of life, it becomes much more clear as the body functions start to deteriorate. So they do have an obligation to make sure that people are informed of where that person's at.

If they're at home, it's a bit more tricky because you don't have an aged care provider team there 24 hours. But you would hope that what's

happening is that they are working very closely with both the palliative care team, as well as the aged care provider care is well-coordinated, and that communication is occurring on a regular basis, a needs basis.

[Craig Gear]

Great. Helen, quick one from you, from Chris. Is doula able to support individuals in residential aged care?

[Helen Callanan]

100%. Yes.

[Craig Gear]

Excellent. Camilla, what's the difference between palliative care and hospice care?

[Camilla Rowland]

Okay, so hospice is the bricks and mortar. It's a place where people go. So in quite a few areas around Australia are hospices which are often a standalone building, which has palliative care specific beds that can also be similar to hospitals that have a palliative care unit, where it's set up to provide that holistic care. So it's literally a place to go.

[Craig Gear]

Great. Linda, Sue wants to know how do we consider the impact of our end-of-life decisions on our family members, for example, where there

might be a resistance to choice, particularly, I suppose, where it comes to VAD.

[Dr Linda Swan]

Yeah, unfortunately, this is a common topic. And often, the issues come about because people haven't had the time to discuss it. Family members feel like it's all a surprise and it's all a bit of a shock, and they don't want their mom or dad to be dying.

And so I think that it goes back to our early conversations about try and have the conversations with your family and the people that care about you as early as possible, because it's your choice.
This is about what you want at the end of your life. And I think it's helping family to understand that this is your choice and that's what you want, and you're asking them to support your choice.

[Craig Gear]

So quick on from Angus, how do I make sure I receive end-of-life care or VAD when I'm at home by a provider? You can get it at home as well?

[Dr Linda Swan]

Yeah, absolutely. About 50% of voluntary assisted dying deaths are in the home. Really, it was envisaged that a lot of them would be, 'cause most people say that they'd rather die in home, rather than in a hospital. So, definitely.

[Craig Gear]

Okay, last one quickly to you Camilla. What strategies can we implement to ensure that there is seamless and effective care coordination between government-funded aged care services and the state-based palliative care programmes? An important question in 30 seconds.

[Camilla Rowland]

Yeah, we need another whole webinar for this. Every state is different. So palliative care is both commonwealth and state-funded for under 65s. So what we need to understand is that those coordination services in each state is different.
So for example, in South Australia, they have a care navigation service, ensuring that people who have their questions answered, who are looking at having a terminal illness, and how do they access the care that's needed.

Every local health district has a different setup for their palliative care services. So the best thing that people can do is actually have a look at what palliative care services exist in their area. And there is a national palliative care service directory that's on our website, that people can put in their postcode, and that will identify what palliative care services in their area.

And as Helen quite rightly pointed out, it is a bit of a postcode lottery. So in some areas, particularly rural areas, it's more likely that there's a GP or a specialist that might have knowledge of palliative care that they need to connect with.

They may not have a specialist palliative care service in their area. So the coordination, we definitely need to work on that between the interface between aged care and palliative care, for sure, now that the act has come in.

[Craig Gear]

Yeah, such an important topic, and we wanna make sure that every person, every older person can access good palliative and end-of-life care no matter where they are in Australia. But unfortunately, we're coming to the end of our webinar for today.

Look, I would like to extend a big thank you to our guests for joining us to share their knowledge and insights, and thank you to you, Camilla, to Linda, and Helen. Thanks for being here today.

If you've registered for this webinar, you'll receive a a follow-up email with all the resources and the links that we've mentioned today. And this webinar will be available on the OPAN website in the coming days.

If you'd like to find out more about our past webinars or what's coming up, please sign up for our newsletter. And our next webinar is "The big Q&A part 2," which is a nonstop question and answer succession from you. And that's on Tuesday, the 2nd of December. And we'll include a registration link and a follow-up in our email after this webinar.

Of course, if you have any questions, do not hesitate to reach out to one of our network member advocates, and you can see their contact details on your screen.

It's been a pleasure to be with you today. I'm Craig Gear. Stay well, stay connected, but most importantly, look after each other. Goodbye.

[Announcer]

This webinar is proudly brought to you by the National Network of Free, independent, not-for-profit organisations across Australia, giving a voice to older people at every stage of their aged care journey. OPAN, the Older Person's Advocacy Network.

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