



Voluntary Assisted Dying in Action

# What we've learnt from Victoria & Western Australia





### **Contact**

Visit: [gogentleaustralia.org.au](http://gogentleaustralia.org.au)

Phone: 0468 464 360

Email: [contact@gogentleaustralia.org.au](mailto:contact@gogentleaustralia.org.au)

Write to: PO Box Q46, QVB NSW 1230

ABN: 61 613 668 643

**Go Gentle Australia** is an expert advisory and health promotion charity founded by Andrew Denton to advocate for better end-of-life choices, including the legal option of voluntary assisted dying. The information we produce is backed by evidence and peer-reviewed research.

First published in July 2022.

**© Go Gentle Australia 2022**

This publication is copyright. Apart from any fair dealings for the purposes of study, research, criticism or review, or as otherwise permitted under the Copyright Act, no part may be reproduced by any process without permission from the copyright owner.

If you would like to learn more, visit us at  
**[gogentleaustralia.org.au](http://gogentleaustralia.org.au)**

Voluntary Assisted Dying in Action

**What we've learnt from  
Victoria & Western Australia**



"Dad didn't choose death.

Dad chose life over and over again. He chose it when he knew he would have his insides ripped out.

He chose it when he knew he would have chemotherapy that would make him sick for another six months.

He chose life, he chose life, he chose life.

And when life was no longer a choice, he decided to die on his own terms."

Katie Harley  
Father, Phil 70, Metastatic bowel cancer,  
Voluntary assisted death, Victoria, October 2019

## Contents

	<a href="#">The experience of VAD in Victoria and Western Australia</a>	<a href="#">5</a>
<b>Part 1</b>	<b><a href="#">The difference VAD laws make</a></b>	<b><a href="#">6</a></b>
	<a href="#">The case study of Kerry Robertson</a>	<a href="#">6</a>
	<a href="#">The case study of Mary-Ellen Passmore</a>	<a href="#">8</a>
<b>Part 2</b>	<b><a href="#">Medical perspectives</a></b>	<b><a href="#">10</a></b>
	<a href="#">Professionally rewarding</a>	<a href="#">10</a>
	<a href="#">Good deaths</a>	<a href="#">11</a>
	<a href="#">A powerful palliative effect</a>	<a href="#">12</a>
<b>Part 3</b>	<b><a href="#">A closer look at the Victorian experience</a></b>	<b><a href="#">14</a></b>
	<a href="#">VAD: An interlocking web of safeguards</a>	<a href="#">15</a>
	<a href="#">Who chooses VAD?</a>	<a href="#">18</a>
	<a href="#">How can we be confident a person seeking VAD is not being coerced?</a>	<a href="#">20</a>
	<a href="#">How can we be sure a person seeking VAD is mentally competent?</a>	<a href="#">22</a>
	<a href="#">VAD and palliative care go together</a>	<a href="#">24</a>
	<a href="#">Impact on the doctor-patient relationship</a>	<a href="#">26</a>
	<a href="#">The Invisible Safeguard</a>	<a href="#">28</a>
	<a href="#">Saying farewell: I choose not to suffer</a>	<a href="#">29</a>



# The experience of VAD in Victoria and Western Australia

Victoria's law has been in operation since 2019, providing three years of robust evidence of how voluntary assisted dying (VAD) works in an Australian context. Western Australia's law came into effect in July 2021 and has provided more than a year's worth of evidence and data.

In particular, the Victorian experience makes it possible to examine the concerns raised about VAD (for example, vulnerable people would be killed, or that palliative care would be damaged) and determine whether they have turned out to be true.

Victoria's Voluntary Assisted Dying Review Board, the statutory body tasked with monitoring the law, have published biannual reports<sup>1</sup> containing data and feedback from those who have chosen to use the law, and those who were with them when they died, including family, friends, doctors and carers.

The reports show that the Victorian legislation is operating safely and as intended. Terminally ill people are being helped to die under the circumstances of their choosing with a deep level of compassion, integrity and care. They also make clear that none of the dark predictions about VAD have come to pass. The law is operating within the strict eligibility criteria and safeguards determined by parliament, with a compliance rate close to 100%.

Assisted deaths account for a tiny proportion of total deaths each year – less than 0.5%. There have been no 'wrongful' deaths referred to police, no rogue doctors abusing the system and no evidence of coercion of the vulnerable.

Feedback from Western Australia<sup>2</sup> mirrors the positive Victorian experience. As of July 2022, 682 West Australians had taken the first step to be assessed under the law and more than 170 had died using VAD medications. Demand was between three and four times greater than expected, according to the board overseeing VAD in WA. People who accessed the scheme had an average age of 73. Of those, 65% had been diagnosed with cancer related conditions, 15% were neurological and 8% respiratory.

"We don't see a lot of media, we don't see a lot of attention given to it, and that frankly is as it should be," said WA Health Minister Amber-Jade Sanderson.

"It is just part of the fabric of end-of-life care, and it also came with significant investment in palliative care in WA so that people had a genuine choice."

This evidence is reassurance that VAD laws in Australia are well designed, compassionate and safe.

**"As the program continues to mature, information and feedback reiterates how voluntary assisted dying provides Victorians suffering from a terminal illness a genuine and compassionate choice at the end of life."**

**VAD Review Board Report of Operations July-Dec 2020**

1. Victorian Assisted Dying Review Board reports available here: <https://www.safercare.vic.gov.au/publications?f%5B0%5D=agency%3A751&search=voluntary%20assisted%20dying%20review%20board>

2. Keane Bourke. WA's voluntary assisted dying laws have been in place for a year. Have they served their purpose? July 1 2022. ABC. <https://www.abc.net.au/news/2022-07-01/doctors-reflect-on-wa-voluntary-assisted-dying-scheme-a-year-on/101194566>

## PART 1

# The difference VAD laws make

Families of those who have used Voluntary Assisted Dying laws in Victoria and Western Australia have described the peace of mind and relief that having choice and control gives to dying loved ones. The words they most commonly use to describe these VAD deaths are “peaceful”, “dignified” and “perfect.”

The extent to which the laws are working safely and compassionately is revealed by the case studies of the first people to use VAD in each state.

## Kerry Robertson – the first person to use Victoria’s VAD law

The following account was written after an extensive interview by Go Gentle Australia with Kerry Robertson’s daughters in 2019.<sup>2</sup> A version can also be read in *The Age*.<sup>3</sup>

The daughters of the first Victorian to use the state’s voluntary assisted dying law say their mother’s death was “beautiful and peaceful”.

Kerry Robertson, 61, died in a nursing home in Bendigo on 15 July (2019) of metastatic breast cancer. She was the first person to receive a permit under Victoria’s Voluntary Assisted Dying Act (2017) and also the first to see the process through to its end.

Ms Robertson’s daughters Jacqui Hicks and Nicole Robertson, who were at her bedside, said: “It was a beautiful, positive experience. It was the empowered death that she wanted”.

“We were there with her; her favourite music was playing in the background and she was surrounded by love,” Jacqui said.

**“She left this world with courage and grace, knowing how much she is loved.”**

“That was the greatest part, knowing that we did everything we could to make her happy in life and comfortable in death,” Nicole said.

Ms Robertson was diagnosed with breast cancer in 2010. Despite treatment, the cancer metastasized into her bones, lungs and brain. In March this year, when the

disease had also spread to her liver and the side effects from the chemo were no longer manageable, she made the decision to stop all treatment.

Jacqui and Nicole said their mother had always known what she wanted. “Mum already had an appointment booked to see her specialist the day the legislation came into effect, she made her first request that same day,” Nicole said.

“Mum had always been brave, a real ‘Feel the fear then do it anyway’ mentality to life; it’s the legacy she leaves with us.”

The women said the assisted dying application process went smoothly and took 26 days.

Ms Robertson took the medication on the same day it was dispensed by the statewide pharmacy.

“It was quick, she was ready to go. Her body was failing her and she was in incredible pain. She’d been in pain for a long time,” Jacqui said.

“Palliative care did its job as well as it could. But it had been a long battle. She was tired, the pain was intolerable and there was no quality of life left for her.”

The sisters said the experience had reinforced their belief that anyone who has a terminal diagnosis, is suffering and in intolerable pain, deserves the choice of a voluntary assisted death.

“It is the most compassionate, dignified and logical option for those suffering in the end stages of life,” said Nicole.

## Kerry's cancer history

- **October 2010** – Kerry is diagnosed with breast cancer. Has lumpectomy, lymph nodes removed, radiation and chemo.
- **March 2015** – Kerry requests scans to be completed which reveal that her cancer has metastasized in her bones. She begins radiation and bone regrowth injections.
- **December 2015** – the cancer spreads to Kerry's lungs.
- **January 2016** – Kerry starts a long-term chemo plan. Scans show that there are tumours in her brain.
- **December 2018** – Kerry is hospitalised twice to manage her pain, but this provides only short periods of relief.
- **March 2019** – the cancer spreads to Kerry's liver. Managing side-effects is affecting quality of life. Kerry decides to stop all treatments.
- **May 2019** – Kerry is admitted to hospice, struggling with pain, nausea and vomiting, and an inability to walk unaided. Her pain medications are adjusted again, with no relief.
- **June 2019** – Kerry moves into a nursing home, begins to decline rapidly.

## VAD Process

- **19 June** – initial verbal request to coordinating doctor and initial assessment are completed.
- **2 July** – second verbal request is made to consulting doctor and secondary assessment completed.
- **7 July** – third verbal request, written request and person of contact paperwork completed and submitted.
- **9 July** – permit is granted, script is sent via registered post.
- **12 July** – appointment is made with statewide pharmacy to meet with Kerry.
- **15 July** – medication is dispensed; Kerry takes it the same day.

---

3. Interview with Nicole Robertson and Jacqui Hicks, Go Gentle Australia, 29 July 2019 [https://www.gogentleaustralia.org.au/the\\_first\\_to\\_use\\_voluntary\\_assisted\\_dying\\_law](https://www.gogentleaustralia.org.au/the_first_to_use_voluntary_assisted_dying_law)

4. Melissa Cunningham 'She left with courage and grace': Daughters farewell Victoria's first person to access assisted dying' The Age Aug 4 2019 – <https://www.theage.com.au/national/victoria/she-left-with-courage-and-grace-daughters-farewell-victoria-s-first-person-to-access-assisted-dying-20190802-p52d97.html>



Kerry Robertson



Kerry and her daughters Jacqui (left) and Nicole (right)





Mary Ellen Passmore and family. Image: Aaron Fernandes/SBS News/NITV

## Mary-Ellen Passmore – The first known person to use WA’s VAD law

In July 2021, a 63-year-old Indigenous woman from Perth became the first identified Western Australian to use the state’s Voluntary Assisted Dying law. Her story was told to Go Gentle by her family. It was also published in *The West Australian*<sup>9</sup> and SBS<sup>10</sup>.

Mary-Ellen Passmore, a Wongatha-Yamatji woman, died in Perth on 29 July of motor neurone disease (MND). She was one of the first to be assessed under Western Australia’s Voluntary Assisted Dying Act.

Her children, Chontall, Challan and Charleton, her sister, partner, and medical staff were all at the bedside. The family described her death as “beautiful”.

“All were singing along to ‘Hallelujah’, including her doctors,” her sister said.

The family said Mrs Passmore had confirmed her choice multiple times before accepting the medication. She thanked her doctors and VAD coordinator and “gave them her love”.

Mrs Passmore had applied to be assessed for VAD soon after the law came into effect on 1 July.

“I feel very honoured to choose when and where I can die,” Mrs Passmore said. “I am excited because I won’t have to suffer any more.”

Mrs Passmore’s family issued a brief statement after her death, saying she had received excellent care from everyone involved in the VAD process.

“We wish to express our gratitude that our proud Black mother, daughter, grandmother, sister, aunty, niece, cousin, godmother, friend, and mentor Mary-Ellen Passmore has been able to have her choice of a dignified death, voluntary assisted dying, finally fulfilled.

“We wish to thank the campaigners, the medical professionals, the families, and the state politicians who fought for the right thing – for the law to catch up and allow for choice and dignity.

“We would especially like to acknowledge and give our loving thanks to those who did not get to have the choice, and those who love them, for sharing their hearts and stories to help bring about this reform. We see you. We hurt for you. You are in our hearts and minds.”

Mrs Passmore said she felt “privileged and grateful” to have the choice of an assisted death.

She had lived with MND, a degenerative neurological condition, for up to 12 years and received a formal diagnosis in 2015. In the past few months her pain had become unbearable.


She had become totally bedridden, had difficulty speaking and swallowing and was fed through a tube.

“It is terrifying being trapped by your own body and it’s a relief to know there will be an end to my suffering,” she said.

5. Rangi Hirini, First known Aboriginal voluntary assisted dying (VAD) patient Mary-Ellen Passmore dies in Perth hospital, July 30 2021, *The West Australian* <https://thewest.com.au/news/health/first-known-aboriginal-voluntary-assisted-dying-vad-patient-mary-ellen-passmore-dies-in-perth-hospital-ng-b881946986z>

6. Aaron Fernandes, ‘I’m at peace’: Aboriginal grandmother among first to use WA’s new voluntary assisted dying laws, July 30 2021, SBS, <https://www.sbs.com.au/nitv/article/2021/07/30/im-peace-aboriginal-grandmother-among-first-use-was-new-voluntary-assisted-dying>



A photograph of two men standing outdoors. The man on the left is younger, with dark hair, wearing a light blue and white checkered shirt and a blue patterned tie. The man on the right is older, with grey hair, wearing a dark blue zip-up sweater over a blue and white checkered shirt. They are both smiling. In the background, there is a dark-colored car and lush green trees.

**"We see patients considerably comforted by having a choice. We haven't had any case where we've thought VAD wasn't justified, and we haven't had any cases where we had any doubt about consent."**

**Professor Michael Dooley, with colleague David Seymour, Statewide Pharmacy Service**



## PART 2

# Medical perspectives

Medical practitioners in Victoria and WA describe the benefits of being involved in the voluntary assisted dying process.

## Professionally rewarding

### Dr Peter Lange, geriatrician (VIC)

You're required to ask people the nature of their suffering, and I was a bit ashamed to see that my practice had unconsciously been to direct people to the suffering that I could relieve. So, I might have talked about suffering but the next immediate follow up question might have been how is your pain, how is nausea and those kinds of things which are more amenable to treatment. So, after starting to assess patients I realised that the nature of their suffering was often not those immediate symptoms but might well be a loss of purpose and dignity. I think it has changed my practice outside VAD.

### Dr Nola Maxfield, GP (VIC)

It certainly added an extra dimension to my practice, and to the people that I've been involved with, because they've been very grateful for the fact that somebody local was providing it.

I think it's improved the relationship I've had with those people because we've been able to have discussions at a deeper level than I would have done with those people otherwise. And I think it's more honest than some of the other treatments we do, knowing that they're futile.



### Dr Angela Cooney, GP, (WA)

The people [involved in VAD] are really special. Not everybody can do this work. Not everybody wants to do this work.

It's not easy, and I lie awake at night rehearsing in my mind the scenario, how it's going to go, to make sure I do it right. And I live in fear of getting it wrong so that that person might suffer more.

But the value of the service far outweighs the personal toll of administering it. I feel like it's a basic human right to exert control at this time, when everything else might feel like it is out of your control.

### Dr James Hurley, general diseases physician (VIC)

Working as a VAD physician has enabled me to give back to the community using my medical qualifications in a way that I did not anticipate. At the end of the day, is not the relief of suffering for an incurable illness, on the terms that the patient requests, and to likewise provide comfort to their families, part of being a physician?

## Good deaths

### Dr Clare Fellingham, consultant anaesthetist (WA)

Overwhelmingly, voluntary assisted dying deaths are peaceful, they're dignified, they're calm, they're gentle and compassionate, and they are truly, truly patient centred.

Personally, I found it an immense privilege to be involved so deeply and intimately in another person's life and experiences that I've gained and conversations that I've had with people. And what they've imparted in me has allowed me to cherish the time that I have, and appreciate my own life even more. I now choose to live more broadly, and actively look to seek out the joy in everything. And that is with an immense debt of gratitude to all the people who've shared all of their experiences with me.

### Dr Nick Carr, GP (VIC)

Just starting the process, knowing that they had that as a possibility, has made an enormous difference to their end of life suffering knowing that they regain some control over the end of their lives.

For the people who have gone through the process – and I have been there for a number of people who have taken the medication – it has been, it sounds odd really to describe dying as beautiful, but it has actually been a beautiful experience. It has been so calm. It has been so peaceful.

It's been a positive experience for myself as a doctor. The families generally have described it that way, too. Their loved ones were going to die, anyway, but, in the end, they died comfortably and in a way that was very gentle.



### Dr Simon Towler, intensive care specialist, (WA)

From the start, those people who have asked to have access to VAD have been the total opposite to my ICU experience. They have faced up to their coming death, often with courage, but always with a degree of clarity. They know their time is coming, we will all die.

For the most part they've shared their challenges and suffering with loved ones and friends. And they come to the VAD team politely seeking to end their life with just a little bit more control and dignity and with less suffering.

It has been an absolute privilege to look after people who are showing all of us that facing your own death is an important part of living.

The patients have given so much more back and we have given to them. They are the heroes in the story and will continue to provide for them even if there are impediments. We respect, admire and applaud every VAD patient.

### Dr Gareth Wahl, emergency physician (WA)

I had previously seen a very large number of unplanned deaths with things left unsaid and with both patient and family profoundly distressed and sometimes in pain. These [VAD] deaths are the complete opposite.

One patient chose to die with no one in the room except myself and my required witness. Mostly they've been surrounded by their closest family and on occasion, up to 30 of their closest friends. They've been surrounded by love. And most importantly, it's been how they've wanted. These people have died well. What I get back from this is really tremendously professionally satisfying. I walk away from this feeling that I've helped people. And that is something that my patients are giving me, that is worth much more than what I'm giving them. So yes, there is a cost, but there's a greater personal and professional gain.



## A powerful palliative effect

### **Fiona Jane, Clinical Hospice Manager, Albany Community Hospice (WA)**

In our experience of patients requesting VAD, we've seen improved patient-related symptom control of previously difficult to manage symptoms such as fatigue and anxiety. And this has happened almost as soon as the first assessment has been completed.

The process of VAD assessment acknowledges suffering caused by the burden of the disease process and the patient feels heard that their fear of increased disability, suffering and being a burden on their family is acknowledged.



### **Dr Philip Parente, oncologist (VIC)**

Voluntary assisted dying is exceptionally patient-centred. We're allowing patients to take control when all the appropriate conditions are met in a very controlled way.

It's quite an amazing sight. They feel definitely more at ease, less anxiety, and they feel more in control. It doesn't necessarily mean they take it. Just having the option there gives them control and gives them hope.

### **Dr Peter Lange, geriatrician (VIC)**

We know that some patients have dispensed the medication and have never taken it. Simply having that possibility, knowing that should they find things intolerable, they have that potential, in and of itself, relieves their concern and their suffering.

**A letter written by Phil Ferrarotto, aged 70, who was dying of metastatic bladder cancer, to his VAD doctor Cameron McLaren (right)**

Dear Cam,

I struggle to think of a way to say thank you for what you have done for me. I chose to write it down so that you can never forget.

Thank you for your bravery in administering the medication for me today so that I can finally be at peace.

Thank you for making me a priority in your schedule when I'm sure you have other patients to attend to and a family of your own.

Thank you for being so kind to my family, putting their minds at rest and answering their questions.

Thank you for spending many years of your life studying and working hard in order that you can help people like me. I'm pleased and honoured to have known you for what feels like a fleeting moment.

I am so proud of the job that you have done. And I'm eternally thankful.

Best wishes for your future, mate.

- Phil

To hear the full story of Phil's VAD journey, click or scan the QR code to listen to Better Off Dead Season 2, Ep 3, 'Lucky Phil.'



**"I think we have to ask why we are here. The only person whose opinion matters is the person in the chair or the bed. That's who I'm here for, the people who are fighting for something that they want."**

**Dr Cameron McLaren, medical oncologist**

**PART 3**

## A closer look at the Victorian experience

When Victoria's Parliament passed the Voluntary Assisted Dying Act in 2017, it was described as "the most conservative law of its kind in the world".<sup>52</sup>

In the 160 hours of debate that preceded its passing, every clause of – and each of the 68 safeguards built into – the law, was forensically interrogated.

Now three years into its operation, we can see how those safeguards work, and whether or not they've proved to be effective.

In this section, rather than hearing from commentators or critics who are once-removed from Victoria's law, you can hear directly from those at its frontline.

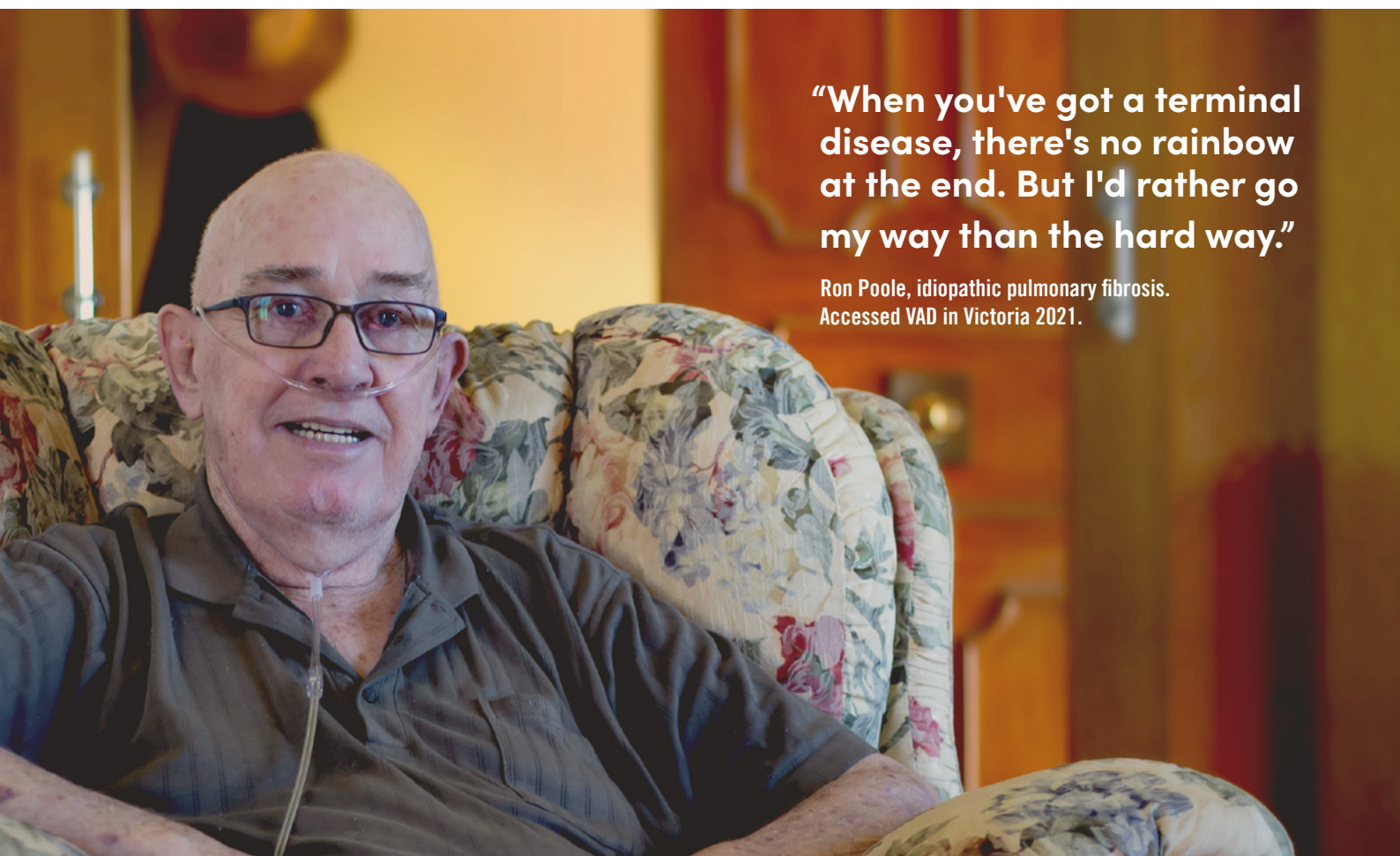
Drawn largely from extensive interviews originally recorded for the podcast series, *Better off Dead*, here are the voices of the terminally ill who chose VAD in the first two years of the law; their families; GPs;

specialists; palliative care physicians; pharmacists who delivered the life-ending medication; VAD care navigators; and members of the Voluntary Assisted Dying Review Board.

If you would like to hear some of their stories in greater depth, throughout this section you'll find QR codes that will link you with some of the episodes.

In tandem with the Voluntary Assisted Dying Review Board's most recent report, we hope this will help provide you with an understanding of how Victoria's VAD law actually works; who it works for; and why it is a necessary option for some at the end of their life.

You can access the VAD Review Board's reports here at the Safer Care Victoria website: [bettersafercare.vic.gov.au/about-us/vadrb](https://bettersafercare.vic.gov.au/about-us/vadrb)



**"When you've got a terminal disease, there's no rainbow at the end. But I'd rather go my way than the hard way."**

Ron Poole, idiopathic pulmonary fibrosis.  
Accessed VAD in Victoria 2021.



## VAD: An interlocking web of safeguards

**“Evaluating a VAD law must be based on how it works as a whole, and not by considering individual provisions in isolation. Numerous eligibility criteria for accessing VAD work together in these laws. Concern about one criterion when considered in isolation may resolve if all criteria are considered as a whole.”**

Professors Ben White and Lindy Willmott, QUT's Australian Centre for Health Law Research

### You have to bring VAD up with your doctor

People have to come and specifically ask for it. They're only going down that track if they really want to go down that track.' – **Dr Nola Maxfield, GP, Wonthaggi**

It takes a lot of courage, a lot of discussions with their partners and their children or their parents. Patients are very clear when they request it.  
– **Dr Phillip Parente, oncologist, director of cancer services, Eastern Health**

### If a person seeking VAD does not meet the criteria, they will be ruled ineligible

I've been approached by quite a few people who have asked about voluntary assisted dying. They've got malignancy, for instance, but they don't have a prognosis of less than six months. So, we talked about what the process would involve and how they can go about it further down the track. – **Dr Nick Carr, GP, Melbourne**

We get some people with mental health issues coming to us who may not fit within the eligibility criteria, but they're calling out for help and they're suffering. So, if it's a crisis, there has been occasions where we've have contacted the police.  
– **Susan, one of the VAD Care Navigators, a team of nurses and social workers responsible for guiding people through the VAD assessment process**

### Independent assessments by two doctors look specifically for mental competency and signs of coercion

That's why you have two doctors. You're getting two, potentially three bites of the cherry to make sure that your assessment is accurate ... so that if there is a delirium if there is a fluctuation.... then you wouldn't proceed. – **Dr Andrea Bendrups, general physician and rheumatologist, Royal Melbourne Hospital**

If they are truly ineligible, it will show. So, I do that in all my patients. If I don't think they've got decision making capacity, I can't give them chemotherapy. I can't give someone who can't consent any form of treatment. It's what we do daily day in and day out.  
– **Dr Phillip Parente, oncologist and director of cancer services, Eastern Health**

The person who was going to make that decision literally had to convince the two doctors that this is what he was doing, of his own volition. I think we were asked it every time. Obviously, for Robert, that none of us were forcing him to, do any of this.  
– **Jean Caliste, who supported his son Robbie, 36 and dying of MND, through the VAD process**

### **A person seeking VAD has to state throughout the process that they know what they're requesting**

There's a lot of checks and balances in place. You have to convince them – so that's four, six people altogether – over a period of months, that you are fully understandable of what you're doing, what will happen when you drink those 30 mls of liquid.

– **Ron Poole, 77, dying of idiopathic pulmonary fibrosis, chose VAD**

The most common feedback we get, in terms of a complaint, is how often they have to tell people they want to use VAD. – **Justice (retired) Betty King, inaugural Chair of Victoria's VAD Review Board**

### **Both doctors must explore alternative treatment options**

I had to see two doctors. I had to give permission to my oncologist to forward all my scans, so they had access to my medical history. And the interviews were an hour, and hour and a half each. And they can come up with other strategies. Whether it's pain strategy, or another course of treatment that maybe the oncologist team had not thought about. The first doctor gave me two other options, and I've taken them both. Neither of them has given me a cure, but they've improved my life. – **Fiona McClure, 67, dying of metastatic bowel cancer, chose VAD**

**dying of metastatic bowel cancer, chose VAD**

It's not a tick box exercise, it's far from it. We have a long discussion with the patient where we go through all the options, informed consent and give them the opportunity to ask questions and ask about alternatives. And to think and come back for another discussion if wanted. – **Dr Phillip Parente, oncologist, director of cancer services, Eastern Health**

### **A person seeking VAD can say no at any time**

The doctors and the specialist and the care navigator stressed that so many times, you do not have to, you're not bound by this. – **Jean and Michelle Caliste, who supported their son Robbie, 36 and dying of MND, through the VAD process**

### **A person seeking VAD must make three requests – one written and witnessed – separated by a mandatory, minimum 9-day period between the first and final requests**

So that there's a clear intention that it isn't made as a one-off when they might have been under the influence of drugs or anything else – **Dr David Speakman, chief medical officer, Peter MacCallum Cancer Centre**

### **On top of the two assessing doctors, there are many other eyes on a person applying for VAD.**

These include: The VAD Care Navigators; the witnesses to the written request; the nominated contact person who must return any unused medication; the pharmacists from the Statewide pharmacy; hospital staff and other members of a person's treatment team; the Secretariat reviewing the documentation; and members of the VAD Review Board.

It's very thorough. There's no little loophole that you can jump through to try and swing the system in your favour. Every dot's got to be there, every T's got to be crossed. If it's not, they just send it back until it is. – **Peter Jones, 65, dying of chronic obstructive pulmonary disease, chose VAD**

I make it very clear to the witnesses that your role is not just to witness the signature, it's to witness the person does have the mental capacity, that's their own free will. They know exactly what will happen when they take the medication and once they get the medication, they don't have to take it. So, the witness needs to be reassured that all that's the case before they can sign. – **Dr John Stanton, GP, West Brunswick**

**The doctors assessing patients are being reviewed in real time – with real consequences (including imprisonment) for failing to act according to the law**

We have the power to refer to AHPRA, the police, the Secretary of the Department of Health, Births, Deaths and Marriages and the Coroner. So, the fact that we review as deeply as we do, in terms of each case, should be a fairly major deterrent to any medical practitioner who is inclined to think 'oh, well, I can just slip this through'. – **Justice (retired) Betty King, inaugural Chair of Victoria's VAD Review Board**

**Even at the last step, the person seeking VAD is assessed for mental competency and reminded that they don't have to take the medication**

There may be a difference between the time that we see them and the time that the doctors had seen them. We work very closely with all the medical staff, but it's been a small number where they haven't been able to demonstrate they're able to take it and those instances, we've had to make a difficult decision to say no. – **Professor Michael Dooley, Director of Victoria's Statewide Pharmacy Service, responsible for delivery of medications to all VAD applicants**

**It takes great determination to see the VAD process through**

It's not just something that you decide now, and it's going to be available tomorrow. There are prohibitive steps in there, that will stop a lot of people doing it. But if someone really feels that they need it, it is available. – **Fiona McClure, 67, dying of metastatic bowel cancer, chose VAD**

I have not seen – and I have been looking, believe me – any type of coercion. It's not an easy process. But neither it should be. This is the ending of a life. And it ought to be treated in a serious manner. Because it's a serious thing to do. – **Justice (retired) Betty King, inaugural Chair of Victoria's VAD Review Board**

It is worth comparing the many steps and safeguards in this law with the ways in which doctors used to (illegally) assist people to die.

Back when I was a young doctor, there were cases where people did have euthanasia. And it happened behind closed doors and wasn't really something that was openly discussed. A lot of it was... the doctors would decide or ... family members would decide, rather than the actual person themselves doing it from an informed viewpoint. – **Dr Nola Maxfield, GP, Wonthaggi**

When I think back over the years when I've helped people at the end stage of life, there was actually no safeguards there for me. There was no peer review. There was no-one looking over my shoulder saying, yes, you're doing the right thing or the wrong thing. – **Dr John Stanton, GP, Melbourne**



## Who chooses VAD?

Reporting from Victoria's Voluntary Assisted Dying Review Board shows that the profile of those who have accessed VAD in its first years is very similar to those who have been accessing similar laws in North America for the last 20 years: They make up a tiny percentage of those who die each year (less than 0.5%); their average age is over 70; and 4 in 5 of them have cancer.

What these figures don't show is that it takes a particular kind of person, with sufficient determination and courage, to go through the VAD application process.

Here's how some of Victoria's doctors, who are qualified to assess for VAD, saw these people, and the choices they made:

The thing that is common to all of them is that they're all really effective people. They know what they want. When you meet them, they're just determined and strong, strong characters.

– **Dr Andrea Bendrups, general physician and rheumatologist, Royal Melbourne Hospital**

They're all people that have thought about it a lot. No-one comes to this sort of decision overnight. It's been in the back of their mind for some time before they actually make the decision. – **Dr John Stanton, GP, West Brunswick**

They're everyday Australians. Usually, they have quite a big extended family, who are present during the process, offering their support. And usually, they're reconciled with their mortality. To ask this question, it takes a lot of courage, a lot of soul searching. They've debated it within themselves for many weeks, if not months prior, and have come to this realisation. Then they have to discuss it with their relatives. And then they'll ask the doctor. It's probably the hardest decision they've made in their lives. – **Dr Phillip Parente, director of cancer services, Eastern Health**

It takes determination to take all of these steps. You have to deeply desire it to choose the path and to stay the path. – **Justice (retired) Betty King, inaugural Chair of Victoria's VAD Review Board**

**331** Victorians have died using VAD medication in the law's first two years of operation.

They ranged in age from **18** to **101**, with an average age of **72**.

**54%** were male, **46%** female.

**86%** died at home. **64%** lived in metropolitan Victoria.

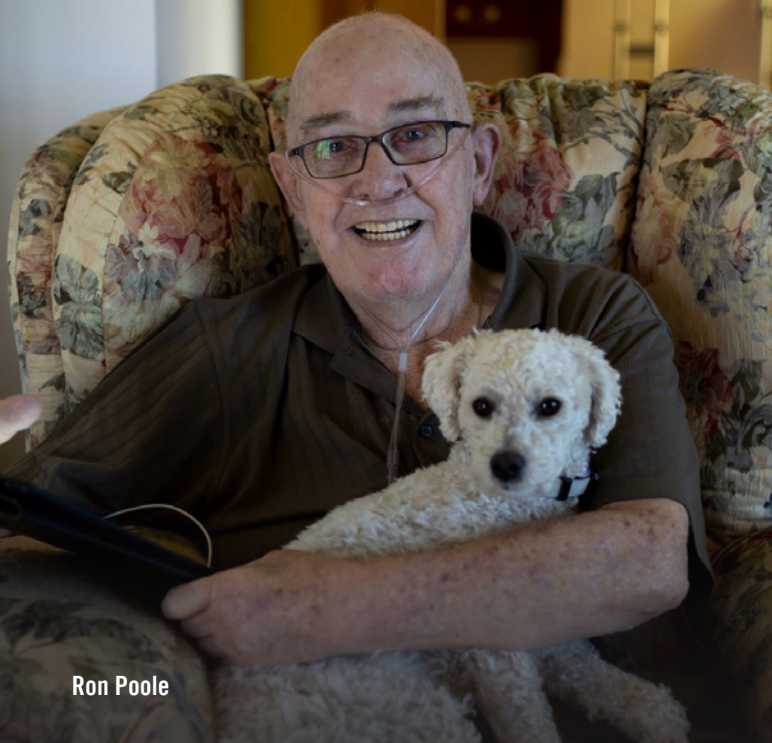
**32%** of those who received medication died without using it.

**58%** of those who received medication died through self-administration, **10%** by practitioner administration.

**83%** had cancer.

I always thought, people who are adamant about accessing voluntary assisted dying are basically control freaks. They like to have control over their life, they always have. And that is true for some of them. But there are some people who... have found themselves in a situation that appalls them and that their suffering is such that they need to do something about it beyond what we can do in palliative care. And they don't want to be sedated, necessarily, they want to leave on their own terms. It's about their existence. Is this existence acceptable to me? No. Can I do anything about it? I'll seek help and see what happens. Is that helping? No. – **Dr Greg Mewett, palliative care physician, Ballarat Health**

They're at the end of a long journey and they're steely-eyed determined that they've got a choice. They know exactly what they're doing. – **Professor Michael Dooley, Director of Victoria's Statewide Pharmacy Service, responsible for delivery of medications to all VAD applicants**



Ron Poole



Fiona McClure with husband Wim



Peter Jones

## Why I chose VAD: Three Victorians explain

When I spoke to my specialist about it, I said, 'so what's the end result?' He said, 'You will get to the stage where you cannot breathe by yourself, I'll put you in hospital on a machine'. And I said, 'That will never happen. I'm not going to be just lying there, hooked up to a machine. That's not a life.'

**Ron Poole, 77, idiopathic pulmonary fibrosis.  
Died April 2021.**

I had three lots of chemotherapy last year. When you look at the scans and all the masses are growing, and it's moved into your lungs, then you know that things aren't good. The best hospital in Australia has sent me home without further treatment. That says it all. Things are happening within my body that I can't control.

**Fiona McClure, 67, bowel cancer that spread to her ovaries, abdomen, rectum and lungs. Died May 2021.**

My lung physician... said, 'Well... you don't need to do any more lung tests, because there's nothing there to test'. It's like walking around with a straw in your mouth trying to suck in enough air. There's no cure for it. Your lungs don't regenerate. I would be bedridden the whole time. ... massive amounts of morphine. Anti-psychotics. It's not a life I find attractive at all.

**Peter Jones, 66, chronic obstructive pulmonary disease.  
Died March 2021.**

Hear Ron, Fiona, and Peter, three Victorians from very different backgrounds, explain why they chose to pursue VAD in *Better Off Dead* Season 2, Ep 5, 'I Choose Not to Suffer.'



## How can we be confident a person seeking VAD is not being coerced?

### The core of voluntary assisted dying is just that – it's voluntary

As with competency, doctors who assess for VAD also receive training in identifying coercion. This is additional to the skills they have already developed through years of practising medicine.

I'm always assessing when I see a patient, their relationship with their families and how that works. Not just in the VAD sense, but in palliative care. Is someone being coerced into having surgery, or are they being coerced into having chemotherapy? We've been doing this for a long time.' – **Dr Greg Mewett, palliative care physician, Ballarat Health**

You need to see that they are using their own words and that they're not being coached. That somebody else is not speaking for them or over them.

– **Dr Nola Maxfield, GP, Wonthaggi**

### Capacity confirmed

The need to demonstrate that a request for VAD is voluntary is constantly emphasised to those applying, and their families.

It had to be me every time. It needed to be my questions. And they needed to prove that it was me wanting it rather than I wasn't being coerced. And there was no benefit to anyone else if I took the drug. It was a big thing. They had to see that I had chosen that path. – **Fiona McClure, 67, dying of metastatic bowel cancer, chose VAD**

She (Helen's doctor) really laid it on the line, and just about yelled at Helen's face: 'Do you want to do this? Are you sure, are you sure, are you sure?' And the witnesses are watching all of this and then they've got to sign that a) Yes, she wants it, b) she hasn't been coerced, she's doing it of her own free will.

– **Reg Jebb, whose wife, Helen, 75, died of motor neurone disease**

### Patient resolve

The nature of the people applying for VAD has, itself, turned out to protect against coercion. Only the most determined get through the process.

The idea that anybody could get through a fraction of the process if they weren't completely committed is laughable. – **Dr Peter Lange, geriatrician, head of Acute Medical Unit, Royal Melbourne Hospital**

I thought the greatest challenge was going to be feeling comfortable in myself that there was no subtle coercion from somebody else. But I can tell you these people, there's not been a sniff of coercion in any of them. – **Dr Andrea Bendrups, rheumatologist and general physician, Royal Melbourne Hospital**

There's that many fail-safes I just don't know how you could ever get through coercing someone. You're assessed for dementia, you're assessed for appropriateness, you're assessed for the illness, you've got to make the request about 10 times in the end. It's almost impossible. It's over the top. – **Dr Kristin Cornell, whose father, Allan, 74, died of motor neurone disease**

For those familiar with every VAD case in Victoria, there have been no red flags raised.

It's hard to duress someone for months, and then duress them into actually saying I want to die, and duress them into picking up the medication and drinking it. I think you have to deeply desire it to choose the path and to stay the path. I have not seen – and I have been looking, believe me – I have seen no indication of any type of coercion.

– **Justice (retired) Betty King, inaugural Chair of Victoria's VAD Review Board**



*We haven't seen any aspects of coercion at all. They're at the end of a long journey and they're steely-eyed determined that they've got a choice and they know exactly what they're doing. And it just cements in your mind ... the intolerable suffering that they've been enduring, to be able to self-administer a medication to do that.*

**– Professor Michael Dooley, Director of Victoria's Statewide Pharmacy Service, responsible for delivery of medications to all VAD applicants**

In fact, the only reported examples of coercion have been of people trying to persuade loved ones NOT to pursue VAD.

Every other patient has had relatives trying to talk them out of it – tearful, we don't want you to go. To soldier on in the face of begging requests from relatives shows incredible conviction.

**– Dr Andrea Bendrups, general physician and rheumatologist, Royal Melbourne Hospital**



Betty King at the recording of the final episode of Better Off Dead

**“You can apply 20 times. But if you’ve not got a diagnosis of a terminal illness together with a prognosis of less than six months, then you’re not going to be eligible.”**

Betty King

Hear Justice Betty King, inaugural Chair of the VAD Review Board and doctors, palliative care physicians, pharmacists, and families discuss the numerous safeguards that protect against coercion in Better Off Dead Season 2, Ep 7, ‘The C Word’.



## How can we be sure a person seeking VAD is mentally competent?

Under the Act, a person must be able to demonstrate that they have decision-making capacity in relation to VAD. They must show that they understand what it is they are asking for; the consequences of that choice; and that they can withdraw from the process at any time. They have to be able to demonstrate this capacity throughout the entire VAD process.

Although determining capacity is part of the training doctors must do before they can assess a person for VAD, it is also central to their day-to-day work.

As a treating doctor, this is not new – this is not a VAD skill. We've all had to ensure patient comprehension and engagement with the process of therapeutics. That's called doctoring. – **Dr Andrea Bendrups, general physician and rheumatologist, Royal Melbourne Hospital**

There's nothing exact in medical science, but you can be as sure as you can be that a person has decision making capacity. And we make those judgments every day of the week. – **Dr Greg Mewett, palliative care physician, Ballarat Health**

### In law, and in medicine, mental competence is assumed unless there is clear evidence to the contrary.

We test competence and capacity every single day in professional clinical life, because every time we have a conversation with someone, they make a decision about their health care, we're making an assumption of competence. So, the legal test is that people are assumed to be competent to make these decisions for themselves. – **Dr Nick Carr, GP, Melbourne**

### How do doctors determine mental capacity?

You need to say that they're with it and they know what's going on. All the things that you would normally do for somebody if you're looking to see if they're developing dementia or mental illness, that's

affecting their cognitive states. So, you need to see that they're providing sensible answers and having an intelligent discussion with you. – **Dr Nola Maxfield, GP, Wonthaggi**

Families reported that doctors were scrupulous in establishing consent throughout the process, the caution and repetition of questions sometimes leading to frustration.

Helen, must have – and I'm not exaggerating here – Helen would have been asked, and confirmed, in this whole process at least 50 times She understood [why] but because it happened so often, she was, like, how many times do you have to bloody say it? How many times is enough? – **Reg Jebb, whose wife, Helen, 75, had motor neurone disease and chose to pursue VAD**

If either doctor has doubts about a person's capacity, the Act says they must refer them to a specialist, such as a psychologist or geriatrician, for further evaluation.

If I was concerned that their mental state was a bit borderline, then I would get an opinion from someone, whether a psychologist or a neuro-psychologist. So, we all know that we can get back-up, we can get a more detailed professional opinion if we need to. – **Dr Nick Carr, GP, Melbourne**

If there is a delirium, if there is a fluctuation, then you don't proceed. If you're remotely concerned that the way they present between these different consultations is significantly variable, then you wouldn't proceed. – **Dr Andrea Bendrups, general physician and rheumatologist, Royal Melbourne Hospital**

### Being depressed does not automatically equate with a lack of mental competency.

A lot of people think that depression equals an inability to make a competent decision. It's not surprising if you have a terminal illness that you have a degree of depression. Most doctors are good at determining that, and the coordinating doctors, rather than necessarily referring off to a psychiatric report, say 'I note a history



**“In the first assessment, what you’re really doing is checking competency, decision making capacity, and looking for coercion. This is not a VAD skill. It’s called doctoring.”**

**Dr Andrea Bendrups, rheumatologist and general practioner, Royal Melbourne Hospital**

of depression six months ago, person was treated, et cetera’, and they talk about the steps that have been taken in relation to whether or not it affects their cognitive impairment. – **Justice (retired) Betty King, inaugural Chair of Victoria’s VAD Review Board**

### **A person seeking VAD has to able to demonstrate competency.**

This all the way through to the end of the application process, when the pharmacists deliver them the medication.

Each time you think you’ve got to the final step, there was another step and another step. And it was extremely difficult because right up to the very end, she had to be able to express her wishes.

– **Lisa Hogg whose mother, Margaret, 82 had the neurodegenerative disease, corticobasal syndrome**

You have to assess whether they understand the information and whether they’re able to retain it, and then make a balanced decision about that information, and then communicate it to us.

– **Professor Michael Dooley, Director of Victoria’s Statewide Pharmacy Service, responsible for delivery of medications to all VAD applicants**

Sometimes, even at this final stage, a decision is made that the person is no longer mentally competent.

He was an elderly man with a mesothelioma of his abdomen. And when I saw him, he met all the criteria, but by the time the Statewide Pharmacist went to visit he no longer had the mental capacity to make decisions. So, he died receiving palliative care and not taking the medication. – **Dr John Stanton, GP, Melbourne**



## VAD and palliative care go together

Palliative care has existed in Australia for 45 years and is ranked second in the world, behind the UK. Despite its high standard, that it cannot help everyone is beyond dispute. Its peak national body advises:

While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal care. – **Palliative Care Australia**

This reality is confirmed by those who work in palliative care.

I've seen bad deaths, and I've heard of bad deaths, in specialist palliative care units. If people say 'just come over to us and everything's fine', it's just rubbish. There are bad deaths in lots of different settings. – **Dr Greg Mewett, palliative care physician, Ballarat Health**

It is also confirmed by those who have watched people they love die painfully.

He was in a very good hospital, had the best of medical care, but he was in and out of consciousness and he couldn't take morphine. And just such incredible pain. And then ten days of downhill and watching him because they then don't feed them and everything's turned off, and they just wait, really. He was a big man, nearly six four and pretty solid, and by the end, I could pick him up. – **Fiona McClure, 67, dying of metastatic bowel cancer, describing the death of her husband**

When Palliative Care Australia says that 'complete relief of suffering is not always possible', it is acknowledging that the process of dying can be complex and involve far more than simply pain. Often, this is what is driving people's requests for VAD.

She was virtually unable to do anything for herself. She was hoisted up in a sling with no pants on being transferred from her chair into the toilet, in front of staff. She was losing her ability to swallow, and she was starting to choke on her food and particularly on drinks. She got to the

stage, she couldn't even turn herself over in bed, so she couldn't make herself comfortable at any point. Mum knew that this was going to get worse. Her suffering was suffering in the larger sense. There's nothing they could have done. There was no drug, no treatment, as no surgery that would make her condition go away. In terms of palliative care, there was really nothing that they could offer her apart from occasional painkillers. – **Lisa Hogg whose mother, Margaret, 82 had the degenerative neurodegenerative disease, corticobasal syndrome. Margaret chose VAD**

It is often argued, by those who oppose VAD, that palliative care must be given full priority before people can be offered other choices. But the lesson from Victoria is that the two go together.

In the lead up to the introduction of this, there was lots of talk about how this was going to undermine palliative care. And that patients were not going to get to palliative care because they take this route. And our experience has been that the vast majority of patients are actually under palliative care. They like palliative care, they value palliative care, and they're pleased about it. But they just don't like the end bit. And the idea of control. You know, it does seem to be very compatible with great palliative care. And it doesn't seem to me to be as threatening, and certainly for our patients, it doesn't seem to be this or that at all. – **A/Professor Charlie Corke, intensivist, member of Victoria's VAD Review Board**

Without palliative care, we would have been completely stuck. It was a huge part of dad's end of life. They were wonderful. But it's a spectrum. We literally palliated him for 36-48 hours waiting for the VAD medicine to come through the door. And I don't know how long it would have gone on for, but to say that without palliative care that you shouldn't need VAD, it's just not true. Dad didn't want to lie there breathless for 48 hours before his end. He was like

'I've been able to extend my life with my family, living in a way that I never expected, and being okay with all of that. But now here's my point where I'm not okay with this anymore.' – **Dr Kristin Cornell, whose father, Allan, 74, dying of motor neurone disease, chose VAD**

## 82% of all applicants for VAD were also receiving palliative care.

Like every other medical treatment in Australia, palliative care is not compulsory. It is our legal right to say 'no'. For people seeking VAD, being in control and allowed that choice was in itself palliative – relieving an otherwise terrible anxiety.

I'm just a different person since the VAD decision. It's just been so much better. And I'm sure there's a lot of people out there who go all the way with this horrible thing, to a horrible end. Now I don't have to do it. I can pick the day. So, I'm now having a whole lot better period of pre-mortality than I could ever possibly hope to live with this shit hanging on you, because all these lovely people have said 'we can solve that'. And they do it lovingly, you know?

– **Allan Cornell, 74, dying of motor neurone disease speaking to his daughter, Kristin, about what being eligible for VAD meant to him**

[Palliative care] has a lot of the answers and it makes people comfortable, but it doesn't have all the answers for all the patients. It does not address the feeling that you're losing control. It may address the symptoms, but a lot of the decisions are not made based on pain. In all my patients, it really is loss of autonomy and dignity, and that all they can see is this downward spiral. – **Dr Phillip Parente, oncologist, director of cancer services, Eastern Health**

We don't say to someone with heart disease, 'Well you could either have pills or you can have a stent, but you can't have both.' And the same is true of this. Of course, at the end of life people should have palliative care. If they're interested in Voluntary Assisted Dying, look at that as well. Know what your options are. The two go together. – **Dr Nick Carr, GP, Melbourne**

It's about choice at the end of life. And, even though some chose VAD as an option, in the end it was an option they didn't all take.

I don't see it as a binary and neither do my patients, who see pursuing both as complementary. And indeed, many of them will continue with palliative care and find that does actually tolerably relieve their suffering and they will maybe dispense the medication but simply never take it. That is a very reasonable and speaks to the ability of palliative care to successfully do what it can almost always do.

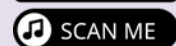
– **Dr Peter Lange, geriatrician, head of Acute Medical Unit, Royal Melbourne Hospital**

## 32% of those who received medication died without using it.

Dying people need help of many kinds. For most, it will be palliative care. For some it will be the spiritual comfort of their deeply held beliefs. For a small percentage it will be the help that assisted dying choice offers. Or it may be a combination of all three. As Australia's most eminent palliative care physician observes, they are all in the same conversation.

Voluntary assisted dying and palliative care go together. They have similar aims in relief of distress, and need to espouse similar approaches of compassion, lack of haste, involvement of family, transparency, clear consent, open reporting. It is against proper loving medical practice, to have rigid provisos that limit what can be done. – **Emeritus Professor Ian Maddocks, palliative care specialist, founding President of the Australian and New Zealand Society for Palliative Medicine**

To learn more about the intersection of VAD and palliative care, listen to *Better Off Dead*, Season 2, Ep 10, 'We, Who Walk Towards Death.'



## Impact on the doctor-patient relationship

Concerns were raised that the legalisation of VAD in Victoria would lead to an erosion, and perhaps breakdown, in trust between doctors and patients. The reverse has proved to be true.

VAD is a special and important part of the doctor patient relationship. The idea that it destroys the doctor patient relationship, I think is upside down. And what we're seeing in feedback is that when a patient reaches out and asks for this, and they get a refusal, that seems like a terrible abandonment of what may well have been a very good long term, doctor patient relationship. And it starkly contrasts with the suggestion by those who oppose VAD that responding to a request would damage the doctor patient relationship and doctor patient trust.

– **A/Prof Charlie Corke, intensivist, member of Victoria's VAD Review Board**

Universally, doctors signed up for VAD because they felt that this accorded with their definition of person-centred care.

When the legislation came out, I thought, 'Patients wanted this, that's the reason it's put in'. We practice patient-centred care, which means we should be providing the services that they want. And that's who I'm here for. – **Dr Cameron McLaren, medical oncologist, Melbourne**

The legislation had been enacted about six months prior, and I was starting to get the questions and I was feeling very, very uncomfortable with not providing the care that I think I should have been providing. I [felt] awful referring them on when I've dealt with them for the last five years. This is part of their disease journey, and I need to be there for them as their oncologist and to help them through this, and if they've got the guts to ask for it, then I should have the guts to enable that to happen.'

– **Dr Phillip Parente, oncologist, director of cancer services, Eastern Health, initially a conscientious objector, now a qualified VAD doctor**

Doctors report that demands of VAD assessments laid out in the law – with their emphasis on exploring a person's suffering and how it's being treated, and on carefully interrogating the voluntary nature of a request – have improved their practice.

It certainly added an extra dimension to my practice, and to the people that I've been involved with, because they've been very grateful for the fact that somebody local was providing it. I think it's improved the relationship I've had with those people because we've been able to have discussions at a deeper level than I would have done with those people otherwise. And I think it's more honest than some of the other treatments we do, knowing that they're futile. – **Dr Nola Maxfield, GP, Wonthaggi**

You're required to ask people what is the nature of their suffering, and I was a bit ashamed to see that my practice had unconsciously been to direct people to the suffering that I could relieve. So, I might have talked about suffering but the next immediate follow up question might have been how is your pain, how is nausea and those kinds of things which are more amenable to treatment. So, after starting to assess patients I realised that the nature of their suffering was often not those immediate symptoms. But might well be a loss of purpose and dignity. I think it has changed my practice outside VAD. – **Dr Peter Lange, geriatrician, Head of Acute Medical Unit, Royal Melbourne Hospital**

We will still assess them and help them the best we can. But they may inevitably decide to go down that [VAD] path, rather than to just continue through to natural death. We find it very rewarding to be able to assist these patients who, for whatever reason, are at the limits of their suffering. It does not undermine our efforts as palliative care clinicians. – **Dr Greg Mewett, palliative care physician**



Most doctors conceded that the mandatory training; the sometimes-demanding nature of assessments; and – in particular – the strict reporting requirements of the law, added considerably to an already heavy workload. Some involved in directly administering VAD reported that it came with an emotional toll. However, this was greatly outweighed by the positive impacts of being part of the process.

My first patient, young person, younger than myself, with end stage cancer, with an amazing wife, full of courage, and with young children, and who had bad disease. That is, lost a lot of weight, becoming increasingly bed bound, and I felt so good within myself when I said, 'Yes, I am going to help you with this.' It was just a privilege. I learned a lot from that patient about courage, about respect. – **Dr Phillip Parente, oncologist, director of cancer services, Eastern Health**

Families, too, were grateful to doctors who had helped people they loved through to the end of their lives.

Medicine isn't just about curing people. It's about helping them to their very last breath. We're asking doctors to be brave to the end, because their patients are being brave. We need these doctors in business. – **Katie Harley, whose father Phil, 70, dying of metastatic bowel cancer, chose VAD**

As a family, we wrote to all the health professionals involved in Mum's circumstance and thanked them. Because they put themselves out there in a way that a lot of people wouldn't be prepared to do. – **Lisa Hogg whose mother, Margaret, 82 dying of neurodegenerative disease, corticobasal syndrome, chose VAD**



In Victoria in the first two years, **234** medical practitioners were trained and registered to assess for VAD.

**147** were GPs. **41** oncologists. **11** specialists in neurology. And **5** specialists in palliative medicine.

Of those, **185** were involved in one or more VAD case.

To learn more, listen to Episode 4 of Better Off Dead Season 2, 'Do No Harm.'



## The Invisible Safeguard

There are 68 safeguards built into Victoria's law to protect vulnerable people from exploitation. However, there is one, extra safeguard that you can't see. It's not written into this – or any – law. Yet it's something that doctors and families see time and again: Courage.

No one is afraid of dying. They're afraid of the manner in which they are going to die. I have never seen anyone flinch. They just drink it. I am in awe of the bravery of people. They are stepping into the unknown. – **Dr Cameron McLaren, medical oncologist, Melbourne**

It takes a lot of courage; a lot of soul searching; a lot of discussions with their partners and their children or their parents, relatives, best friends. prior to coming to me. It's a humbling experience. – **Dr Phillip Parente, oncologist, director of cancer services, Eastern Health**

I ask myself the question, would I be able to do what she did? And I don't know the answer. All I know is that mum was very determined. She ...was a little bit nervous about the process of what would happen as she was dying. But not as frightened as she was of what would happen if she didn't have assisted dying. That was terrifying for her. But I do think having that cup in your hand, and taking that first sip knowing that you're going to die – it took enormous courage. And I just so admire that. – **Lisa Hogg whose mother, Margaret, 82 was dying of the neurodegenerative disease, corticobasal syndrome, and who chose VAD through self-administration**

He was so brave, you know, and I think that full-on moment of realising that you have it and you can do it. It's very confronting, because it's easier to give up, I think, at that point. – **Dr Kristin Cornell, whose father, Allan, 74, was dying of motor neurone disease and chose VAD through self-administration**

Till the day I die myself, it'll be the most courageous thing I've ever seen anyone do. To look a man in the eye and to know that he's about to end your life, but not just to do that, to write him a letter and say thank you, that's courage beyond measure. – **Katie Harley, whose father, Phil, 70, was dying of metastatic bladder cancer and chose VAD through practitioner administration**

It takes determination. You've got to take all of these steps. I'm in awe of all of these people who go through it. I just admire their courage; I admire their strength. – **Justice (retired) Betty King, inaugural Chair of Victoria's VAD Review Board**



**“The idea that anybody could get through a fraction of the process if they weren't completely committed is laughable.”**

**Peter Lange, geriatrician, Royal Melbourne Hospital**

Hear palliative care physicians, pharmacists, and families discuss the numerous safeguards that protect against coercion in Better Off Dead Season 2, Ep 7, 'The C Word'.



## Saying farewell: I choose not to suffer

Once the statewide pharmacy service delivers the medication, the person can take it whenever they choose – there is no mandated timeframe. Or they may choose not to. Most people self-administer; drinking a specially prepared medication – the ultimate act of voluntariness.

For those who can no longer swallow or ingest, the law allows a doctor to administer the medication.

**In the first two years of Victoria's VAD law, 282 VAD deaths were by self-administration.**

**49 VAD deaths were from practitioner-administered medication.**

Because VAD offers control to the person in their dying days, they are able to arrange their farewells in ways that may not have been possible had their disease taken its full course.

Robert was able to plan things. Every one of his friends came and saw him, everyone was able to see him to wish him the best, to give that love. It wasn't that sudden death, you always say, 'Geeze, I wish I'd said that.' Robert planned his funeral. The last words at the funeral were from him. He knew what his coffin was going to look like: half St Kilda and half Melbourne Victory. The music that was chosen, he chose that. He also made recordings for the three of us. How many people don't get that opportunity? – **Jean and Michelle Caliste, who supported their son Robbie, 36 and dying of MND, through the VAD process**

There were about 15 of us, and we took Mum out for the day to [my brother's] home and put her in a big recliner chair, and before we went there, we said, 'Do you want people to feel free to talk to you about it, or do you want them not to say anything?' And she just said she's happy for it to be an open thing, not this big secret. So, she spent the afternoon surrounded by her children, her grandchildren, her great grandchildren. And we all sat around and we chatted, we laughed and everyone in their own time went up to Mum and just had a quiet moment. And we played music, we watched back over old videos of different family events that we'd had from, you know, 20 years ago. It was kind of like her life in a microcosm just there in that, that one afternoon. We kept saying to Mum, 'Look at you, you created this, you know. If you and Dad hadn't met, this... none of us would be here. This is, this is your legacy.' It was just such a lovely thing to be able to have the opportunity to know that, yes, I'm going to die, and I want to have everybody I've loved to be with me just for one more time, all together, and it was perfect.

– **Lisa Hogg whose mother, Margaret, 82 dying of neurodegenerative disease, corticobasal syndrome, chose VAD**

**Victoria's medication has proven to be reliable and effective.**

Of all the patients that we've treated to date, there hasn't been any that have taken the medication, that it hasn't resulted with them passing away. And we haven't had any major complications. That's a reflection of a lot of the hard work and the safeguards that have been put in place. – **Professor Michael Dooley, Director of Victoria's Statewide Pharmacy Service, responsible for delivery of medications to all VAD applicants**



**Every family, and every death, is different, but the overwhelming experience of a VAD death is that, while still deeply sad, it is a peaceful and loving experience**

We were all sitting by the bed. It was like Dad designed those last few moments and it was exactly the way he wanted it. And as the medicines went in, we... even had a bit of a laugh, to be honest, because Mum and Dad always used to argue about who was the snorer in the relationship and once the very first vial went in – it was the general anaesthetic – and the last two breaths that Dad took were these two massive snores, and we all sort of had a bit of a laugh. And we were crying and laughing and then Dad just sort of... before he did that, he just looked at us and he said, 'Be happy.' And that was it. It really was, it was beautiful. – **Katie Harley, whose father, Phil, 70, was dying of metastatic bladder cancer and chose VAD through practitioner administration**

So, the moment he had it... I think it took about half an hour. for him to pass, but to fall asleep straight away was within a matter of seconds, so there was no suffering. And the look on his face – it's like suddenly there was no pained look. It just disappeared. It was the Rob that we knew. Just looked like a baby asleep. It was just all gone. It's like a veil was lifted. It was beautiful. – **Jean and Michelle Caliste**

They write us stories about how it went. They will ring and share. They do that a lot of the time. We have a great big long list of all the comments that everyone has written. The most common words that's in them is peaceful. – **Professor Michael Dooley, Director of Victoria's Statewide Pharmacy Service**



**'Assisted dying gave me my life back'**

28-year-old Victorian Alex Blain chose VAD in January 2021, after 19 rounds of chemotherapy, surgery and radiotherapy to combat CIC Dux Ewing's Sarcoma, an aggressive, rare and fatal cancer.

Three days before he died, Alex wrote that VAD "gave me my life back just as I started dying".

"I handed my treatment and body over to medical professionals for over a year and in many ways lost autonomy over my body," he said.

"I feel empowered and now as it is getting towards the end I know that I have control back.

"I can show myself compassion and choose not to die of cancer. It is a small thing but the peace of mind it has created is immeasurable."

Alex said that applying was straightforward because he fulfilled all eligibility criteria, although VAD "needs to be more widely talked about".

His family said the respect and compassion from medics meant Alex left every appointment relieved and with "a spring in his step".

"The control and the ability to find peace gave him comfort," his fiancée Liz said. "I've come to the conclusion that VAD has very little to do with death and a lot to do with life."

**Click or scan the QR code to hear more about Alex Blain's VAD journey on ABC RN.**





**"I'd like to go out in a pretty dress with pretty pink lipstick and having just had a latté with a girlfriend. That would be a great way to go. I'm looking forward to a glass of champagne after I take the draught."**

**Fiona McClure, 66, metastatic cancer, chose VAD and died in May 2021**

