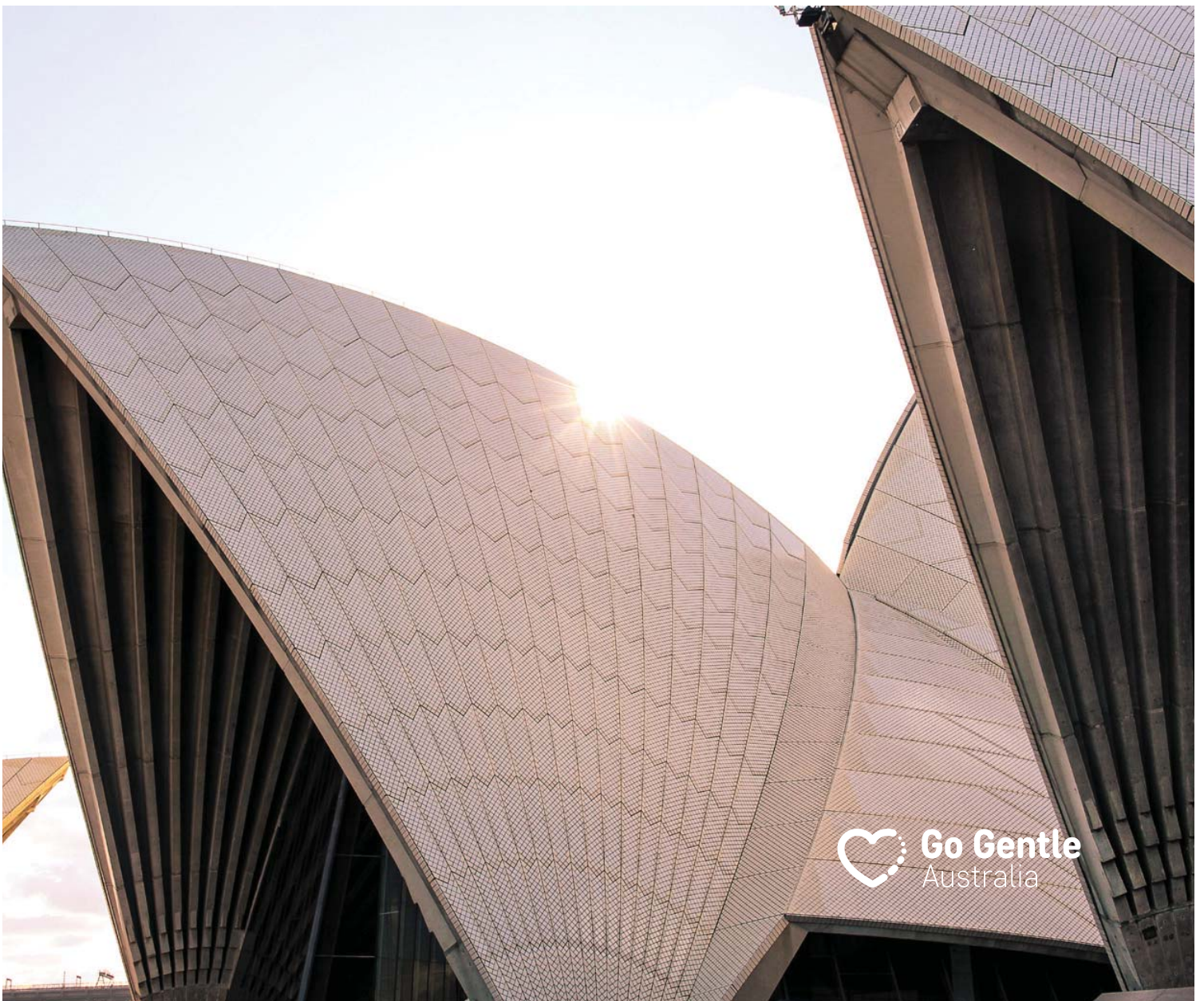


Document tendered by
Mr Steve Oppner
Received by
S. Fujiwara
Date: 8 /Dec/ 2021
Resolved to publish Yes / No

Voluntary Assisted Dying

A Guide to the Debate in NSW

OCTOBER 2021





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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 as 'VAD – A guide to the debate ahead in Western Australia' by **Go Gentle Australia** in October 2019.

Republished with edits in August 2020, November 2020, July 2021 and October 2021.

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Voluntary Assisted Dying

A Guide to the Debate in NSW

OCTOBER 2021

"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

Introduction	6	Part 3: What we've learnt from Victoria	30
The Debate Ahead: Clock and Bomb	6	VAD: An interlocking web of safeguards	31
Part 1: Some facts	7	Who chooses VAD?	34
Why VAD now? The unintended consequences of our existing laws	7	Why I chose VAD: Three Victorians explain	35
VAD laws in Australia and New Zealand	8	How can we be confident they are not being coerced?	36
Who this law is for: The limits of palliative care	9	How can we be sure they are mentally competent?	38
It's not about pain, it's about suffering	10	VAD and palliative care go together	40
Part 2: Questions raised by MPs	12	Impact on the doctor-patient relationship	42
Will this law encourage elder abuse and coercion?	12	The Invisible Safeguard	44
Shouldn't we just resource palliative care better?	14	Saying farewell: I choose not to suffer	45
Won't VAD lead to doctor shopping?	16	Part 4: Four questions for legislators	48
Can we trust doctors to do the right thing?	17	Does this law make end-of-life practices in NSW safer?	48
Why is VAD not shown as the cause of death on death certificates?	18	Does this law protect religious freedom?	49
Is it true people are choosing VAD because they feel a burden?	19	Does it make end-of-life practices in NSW more equitable?	50
Why a 12-month timeframe for people with a neurological disease?	20	Does this law meet community expectations?	51
Why is there a 5-day waiting period between first and last request?	22	Part 5: How have other states departed from Victoria's law and why?	52
What is the difference between VAD and suicide?	23	Graphic: How Australian Medical bodies have changed their views about VAD	54
Is VAD medication reliable?	25	Part 6: Why facts matter	56
Shouldn't there be a mandatory psychiatric examination?	26	End notes	58
Why is a person assessed on suffering and not just pain?	27		
How the Victorian VAD law works: The case study of Kerry Robertson	28		

Introduction

The debate ahead: Clock and Bomb

We all know what a clock is. A precisely made piece of machinery, consisting of many parts and designed to do one thing: tell the time accurately.

The voluntary assisted dying bill you are about to consider is like a clock: A piece of legislation – designed with careful input from public health experts, senior clinicians and others – to offer terminally ill people in the last stages of their illness (and only those people) a choice about the manner and timing of their death.

It is very similar to the VAD ‘clock’ that has been operating safely and effectively in Oregon since 1997, in Victoria since June 2019, and Western Australia since July 2021.

But what happens if you take a clock apart and put all its component pieces on a bench?

It no longer looks like a clock. In fact, it becomes possible to argue that the pieces, when examined individually – this spring, that gear – may not be parts of a clock at all. They might be a bomb.

In the debates that lie ahead, opponents of this legislation – just as they have done in other parliaments – will use every tactic they know to make you forget that VAD is a clock. Instead, they’re going to try and make you think of it as a bomb.

They know that, in their opposition, they represent only a small minority of Australians. They know that years of credible, peer-reviewed evidence from overseas, as well as two years’ worth of data from the operation of Victoria’s VAD law, shows that the ‘clock’ works as intended. They know that the doctors and nurses who have talked about the need for this law and the protections it provides, are hard to deny. And they know that, as VAD has been made legal in five other states, their arguments against it have been scrutinised and studied from every angle – and ultimately rejected.

Faced with these realities, those opposing reform have only one tactic left: to use the parliamentary debate, which allows that the ‘clock’ of legislation be pulled

apart, to try and make you lose sight of the fact that it was ever a clock in the first place.

To do this, they will employ a debating technique known as the ‘Gish gallop’.¹

The Gish gallop focuses on overwhelming an opponent in a debate with as many arguments as possible, without regard for the accuracy or strength of those arguments.

How does it work? Here’s New Hampshire legislator, Nancy Elliott, spelling it out to local campaigners at an international anti-euthanasia convention held in Adelaide in 2015:

*When you have lots of arguments, if one argument gets blown out of the water, you still have more, and each argument will reach somebody else... You only have to convince legislators that they don’t want this bill. You don’t have to win their hearts and minds. All you have to do is get them to say, ‘not this bill’.*²

In the long hours of debate that lie ahead, through the blizzard of arguments that will confront you, the crucial thing to keep in mind is this:

Who is this law for, and how does it work to help those people – and only those people – at the end of life, who no longer wish to suffer?

In other words, never lose sight of the clock.

“Evaluating a VAD law must be based on how it will work as a whole, and not by considering individual provisions in isolation... Concern about one criterion when considered in isolation may resolve if all criteria are considered as a whole.”³

**PROFESSORS BEN WHITE AND LINDY WILLMOTT,
QUT’S AUSTRALIAN CENTRE FOR HEALTH LAW RESEARCH**

PART 1

Some Facts

Why VAD now? The unintended consequences of existing end-of-life laws

The law in NSW has long recognised a person's right to refuse medical treatment – even if this goes against medical advice.

A person can legally refuse medical intervention, food, and water, with the intention of hastening their death – although this process can be slow and psychologically painful, sometimes spanning weeks. The law does not call this suicide. Instead, it sees it as a person's legitimate choice and one that must be both medically supported, and legally respected.

In NSW, a person also has the right, if they have mental capacity, to decide when life-sustaining equipment is removed or switched off; feeding tubes, dialysis, respirators – even if their medical team disagrees.

NSW law also permits others to make potentially life-ending decisions on our behalf:

- In some cases substitute decision-makers can refuse medical treatment on behalf of a person who lacks capacity, which can result in their death.
- Doctors can sedate a dying person into a coma from which they will never awaken, in order to ease suffering.

This 'terminal sedation', as it is sometimes known, can hasten death. This was confirmed in 2018 by current Federal AMA President, Dr Omar Khorshid, who told journalists:

We shorten patients' lives regularly if that is the right thing to do at the very end of life.⁴

And, of course, NSW law permits suicide. Tragically, this is an option too many terminally ill Australians have taken.

In short, in the absence of voluntary assisted dying legislation, the legal options available to people in NSW who are suffering at the end of life are either to wait out a potentially painful death, hope their doctor will end their suffering, or take matters into their own hands.

Voluntary assisted dying puts choice and control back in the hands of the dying person and respects patient autonomy; a cornerstone of medical law and practice.

This is why five state parliaments have passed VAD laws:

- So that we have a legal right to be protected from unnecessary suffering at the end of life
- So that doctors can be protected in law, and guided by regulation, when doing what many currently do in the shadows
- So there can be more compassionate choices than our current laws allow if we are dying and suffering intolerably.

VAD laws in Australia and New Zealand

The NSW Parliament last debated voluntary assisted dying (VAD) in 2017, when no Australian state had passed such legislation. That bill was defeated by just one vote in the Upper House. Since then, Australia's VAD landscape has transformed. Now, NSW is the only state *without* a VAD law.

The fact that 17 million Australians are now legally entitled to VAD reflects a dramatic shift in political sentiment on end-of-life care.

- Victoria led this change, becoming the first state to enact a VAD law in December 2017. The Victorian Act commenced on 19 June 2019, after an 18-month implementation period.
- In December 2019, Western Australia followed suit, passing legislation which commenced operation on 1 July 2021.
- Tasmania enacted its VAD law in March 2021, followed by South Australia in May and Queensland in September.
- New Zealand, too, endorsed an End of Life Choice Act by national referendum, with the law due to commence in November 2021.

Only NSW sits outside what is now a mainstream view that terminally ill people should have a choice not to suffer at the end of life. (The ACT and Northern Territory are prevented from passing VAD laws by the federal government.)

All of Australia's laws follow a similar framework – coined the 'Australian model' of VAD – which limits medical assistance to die to terminally ill adults of sound mind who are suffering intolerably. Each law came about after significant levels of public consultation. Each has built on the strengths (and addresses the weaknesses) of laws that came before. The result is similar, but not uniform, legislation across the states, based on a considered response to the unique characteristics and circumstances of each jurisdiction.

LAW IN ACTION

THE EXPERIENCE OF VICTORIA

Victoria's law has been in operation since 2019, providing two years of robust evidence of how VAD works in an Australian context.

Crucially, 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, publishes biannual reports 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.

Early feedback from Western Australia, where a VAD scheme has been operating for several months, mirrors the positive Victorian experience. This evidence is reassurance that VAD laws in Australia are well designed, compassionate and safe.

For more information on Victoria's VAD law, turn to Part 3 (page 30).

Who this law is for: The limits of palliative care

While palliative care accommodates the needs of the majority of dying people, even the best-resourced care cannot relieve the extreme suffering some endure. This fact is acknowledged universally by responsible organisations and professionals involved in the palliative care industry.

In Palliative Care Australia's own words:

While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.⁵

By its own calculations, the number of patients truly beyond palliative care's help is about 4%.⁶ Other experts put this number higher at between 5 and 10%.⁷ The suffering, as recorded in evidence to multiple Australian parliamentary inquiries, can be savage.

In 2016, 70% of respondents to an Australian Medical Association (AMA) survey agreed with the statement that:

Palliative care and medical treatment cannot adequately alleviate the suffering of some patients.⁸

Although Australia has the second-highest ranked palliative care system in the world,⁹ these responses reflect the reality of modern medicine which can keep us alive longer, but which still has no cure for illnesses like cancer and motor neurone disease.

“Even if good, modern palliative care was available for each and every terminally ill patient – we would still have the ‘nightmares.’”¹⁰

CLIVE DEVERALL, PALLIATIVE CARE WA FOUNDER

It's not about pain, it's about suffering

Dr Roger Hunt, a specialist in palliative medicine for three decades, who sat on the Victorian and WA Ministerial Expert Panels, explains how suffering is much more than just pain:

Dying people have varied and sometimes intense suffering, including physical, emotional and existential suffering. All surveys of palliative patients, including those in most renowned hospices, show they experience multiple concurrent symptoms. Severe refractory symptoms, including suffocation, pain, nausea and confusion, requiring palliation with deep sedation, have been reported in up to 50% of palliative care patients.¹¹

In his book, *The Nature of Suffering and the Goals of Medicine* (2004), Dr Eric Cassell, Emeritus Professor of Public Health at Cornell University, describes suffering as:

An affliction of the person, not the body.¹²

Prof Cassell, a member of the Institute of Medicine of the National Academy of Sciences and a Master of the American College of Physicians, insists:

Not all suffering can be relieved, no matter how good the care ... and with even the very best treatment the suffering of some patients is terrible and unrelenting. Experienced clinicians know that even if you think you have seen the worst suffering possible, given time you will see someone suffering even more.¹³

Suffering at the end of life can be, for some, a condition that is ultimately impossible to palliate. Bone cancer, for instance, can be excruciating and almost impossible to relieve.

For a deeper understanding of suffering at the end of life, we urge you to watch the film *The Broken Hearted* (thebrokenhearted.org.au). It includes the story of Peta Quinlivan from Busselton, WA, whose husband, Russell, died in 2016 of lung cancer:

If people spent all this time with someone who was suffering, they might have some idea of 'he died peacefully'. I don't think so. Yes, he might have been looking like he was peaceful at the end, anyone on that amount of painkillers might look peaceful at the end, and anyone that is so exhausted from what they've been through might look peaceful at the end, but what about all the part leading up to it that wasn't peaceful?

The palliative care response to intractable pain and suffering is terminal sedation, a medically controlled process that is utilised close to the end of life, where a dying person is sedated into a coma.

When – and how quickly – this relief is delivered is entirely in the hands of the treating doctor, some of whom hold strong beliefs about the sanctity of life. Parliamentary inquiries have found that, in order to avoid accusations of intending to hasten death, the delivery of sedatives and analgesics is, sometimes, slowly titrated upwards, which means that control of pain and suffering may take some days to achieve. As nutrition is simultaneously withheld, it can take up to two weeks for the person to die.

Advocates of law reform believe it would be more humane to assist a person with unbearable, irremediable suffering by the administration of drugs (upon request), that cause death in minutes, rather than being administered sedatives and starving to death over several days or even weeks.

68% OF AMA DOCTORS SURVEYED AGREED THAT PALLIATIVE CARE CANNOT ADEQUATELY ALLEVIATE ALL PATIENTS' SUFFERING¹⁴

Dr David Grube, a GP from Oregon with 35 years experience, who has worked within that US state's Death with Dignity Act since its inception in 1997, says in his experience the symptoms of some conditions are much more difficult to palliate – and may lead a person to request VAD. The chart below outlines some of the most challenging conditions and their symptoms:

CLASSIFICATION	DISEASE	SYMPTOMS
Neurological	Motor neurone diseases: Amyotrophic lateral sclerosis (ALS), Progressive bulbar palsy (PBP), Progressive muscular atrophy (PMA), Primary lateral sclerosis (PMA).	Gradual paralysis towards complete inability to move, then ultimately, to breathe: no treatment
Cancer	Stage IV malignancy: beyond treatment; incurable	<p>The symptoms of cancer are more significant than the cause. Many of these occur at the same time.</p> <p>Pain: constant and irresolvable, multi-system</p> <p>Bone metastases: cancer in the bone is the most painful</p> <p>Distention: accumulation of body fluids (abdomen)</p> <p>Open sores: often get infected</p> <p>Weight loss: this causes all other symptoms to be exaggerated</p> <p>Odour: bodily discharges from orifices and skin that cannot be controlled</p> <p>Disfigurement</p> <p>Incontinence: bowel and/or bladder</p> <p>Fatigue: constant and unrelenting</p> <p>Systemic inflammation: a persistent 'flu-like' feeling</p>
Pulmonary	End stage emphysema	Unresolvable shortness of breath/smothering
Cardiac	Congestive heart failure	Smothering/intolerable swelling/angina
Gastrointestinal		(Can also be side effects of treatments) loss of appetite/diarrhea/pain
Genitourinary		Incontinence/vaginal discharge/bleeding/recurrent infections
Central nervous system		Uncontrollable seizures/intractable headache pain
Haematologic	Leukemia, etc	Continuous bleeding/untreatable infections
Dermatologic		Open sores/painful/dressing change problems/infections

PART 2

Questions raised by MPs

Will this law encourage elder abuse and coercion?

Some opponents suggest that family members or carers could pressure or ‘steer’ an elderly person to request assistance to die in order to, for instance, access an inheritance sooner. They point to concerning levels of elder abuse that exist in our community, exposed by Australia’s Royal Commission into Aged Care Quality and Safety.¹⁵

Elder abuse is a serious problem. It is only made possible by abusers acting in what they believe to be secrecy.

A VAD law makes such abuse less likely by bringing practices that are currently happening in secrecy into the light.

Parliamentary inquiries into end-of-life choices in Australia have found that some doctors do, currently, assist people to die, but that they do so ‘without support, without transparency or accountability’.¹⁶

VAD law encourages better practice. It brings regulation and scrutiny to a space that is currently unregulated. It specifically insists that doctors examine questions of competency and coercion. And it offers the vulnerable protections they currently do not have, with strict eligibility criteria and strong safeguards which apply only to those for whom the law is written.

A VAD LAW MAKES ABUSE LESS LIKELY, NOT MORE, BY BRINGING INTO LIGHT PRACTICES THAT ARE CURRENTLY HAPPENING IN SECRET

There is far more involved in accessing assisted dying than merely a patient requesting it. (See page 31, VAD: An interlocking web of safeguards.)

The opinion of medical professionals that the person’s condition meets strict criteria is required. Failure by doctors to follow the rules means they risk losing their licence or going to jail.

Research in jurisdictions where voluntary assisted dying is legal, including in Victoria, demonstrates no evidence of elder abuse as a result of these laws.

“Believe me – I have seen no indication of any type of coercion.”

BETTY KING, QC, CHAIR OF THE VICTORIAN VAD REVIEW BOARD¹⁷

Victoria’s VAD Review Board applies forensic oversight to every stage of the VAD application process. It says:

The Voluntary Assisted Dying Act 2017... is interpreted in a very strict way, and the Board continues to have a very low threshold for errors or inconsistencies in applications in order to maintain public safety.¹⁸

In the first two years since Victoria’s legislation was implemented, compliance has been extraordinarily high. Of the 597 cases where people were issued VAD permits, there have only been eight reports of non-compliance. None were related to eligibility of the applicant, or to the quality of clinical care. There have been no referrals to police or the coroner for further investigation.¹⁹

By contrast, existing end-of-life practices – terminal sedation, and voluntary refusal of food and fluids – involve little, or no, regulation, or oversight. There is no central record of their use and no requirement for doctors to examine capacity of the person or the potential that their decision to hasten death may be as a result of coercion.

Sadly, there will always be those who seek to abuse others. VAD law has been built – and has been shown – to protect against this. (See page 36, How can we be confident they are not being coerced?) It would be far easier for a malicious individual to encourage an elderly relative to overdose on their everyday medication, for example, than it would be to risk the many levels of scrutiny required of the VAD assessment process.

WA's Ministerial Expert Panel found:

... Where voluntary assisted dying is practised, systematic reviews have found that coercion is rare...

In fact:

Anecdotal reports suggest that coercion from relatives is more likely to take the form of an attempt to dissuade the person from voluntary assisted dying.²⁰

It is appropriate to raise concerns about elder abuse and coercion of the vulnerable. But it is morally wrong in doing so to raise *hypothetical* concerns about the abuse of vulnerable people as a reason not to address evidence of *actual* abuse happening right in front of us.

The Victorian, Western Australian, South Australian and Queensland inquiries clearly show that vulnerable people are being mistreated and abused within our medical system because of existing laws.

It is abuse to force vulnerable people to suffer a painful and drawn-out death against their wishes.

It is coercion to leave a dying person the choice of only further treatment (which has become intolerable) or suicide.

It is not the prospect of VAD laws that heightens the risk of mistreatment and abuse, but rather its absence.



Shouldn't we just resource palliative care better?

This is not, and never has been, an either/or debate. Assisted dying and palliative care both have the same aims: to alleviate suffering at the end of life; to help people die well; but also and just as importantly, to help them live well and with dignity in their last weeks and months.

The reality is that both palliative care and VAD are important. However, the view that 'we should not consider VAD until palliative care is fully resourced' is a classic Catch-22. Those who oppose VAD know they can always argue that there are never enough palliative care services, no matter how much money is directed to them, because they can forever shift the hypothetical baseline of what constitutes 'enough'.

Regardless of resources, there are clear limits to the effectiveness of palliative care. (See page 9, Who this law is for: The limits of palliative care).

There are also patients with chronic and progressive illnesses – such as advanced Multiple Sclerosis or motor neurone disease – who, because of the long-term nature of their suffering, do not easily sit within the palliative care system.

As well, some patients do not wish to die a 'medicalised' death, even one in palliative care. According to the Grattan Institute, 70% of Australians wish to die at home but only 14% do.²¹

Why should these patients, and their suffering, be set aside to reach a hypothetical goal of palliative care perfection, when we have the means to help them now?

Although both proponents and opponents of VAD strongly support increased resourcing of palliative care, it is important to remember that Australia already has the second-best palliative care system in the world, just behind the UK. In Australia, NSW performs well. The NSW Government invests \$220 million every year in palliative care, as part of their End of Life and Palliative Care Framework 2019-2024. An additional \$82.8 million contribution over the next four years was announced

in June 2021. This echoes recent NSW Government commitments: \$100 million in 2017, \$45 million in 2019 and \$56 million in 2020.²² This sustained investment is reflected in the state's 147-strong body of palliative medicine specialists; 41 more than Victoria, and more than Queensland, Western Australia and South Australia put together.²³

Claims by opponents that the introduction of voluntary assisted dying laws leads to a decline in palliative care are untrue. A 2018 report commissioned by Palliative Care Australia, looking at the impact of VAD on palliative care internationally, found:

*There is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards ... if anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.*²⁵

It found that physicians sought to improve their knowledge and understanding of end-of-life care support services after the introduction of VAD, and that there was increased access and funding.

Since their parliamentary inquiries into end-of-life choices, the Victorian, Western Australian and Queensland governments have committed extra funding to support and enhance community-based palliative care services.

That palliative care and VAD go together is borne out by Victoria's most recent Voluntary Assisted Dying Review Board report. It showed that more than 80% of terminally ill Victorians who chose a doctor's help to die were also receiving palliative care. This is commensurate with Oregon, where similar laws have been running for more than 20 years, and where 90% of people seeking VAD were enrolled in either hospice or palliative care.

Opponents also argue that as long as full palliative care services are not available to everybody then VAD is not really a 'choice'. This is a simplistic view of how

palliative care and our medical system work. Dr Roger Hunt, a pioneer of South Australian palliative care, and founding secretary of Palliative Care Australia, explains:

A lot of palliative care is done by family doctors in people's homes, in nursing homes, outside of the major hospitals. That's where people spend most of their time toward the end of life. A GP is very well placed, in knowing the patient so well, to be able to provide palliative care. And basic palliative care, in listening, communicating well, understanding the priorities for the person, delivering basic symptom relief, such as pain medications, the relief of other symptoms, is not complex medicine.

Having said that, a GP, and oncologists and other specialists, do need to have specialist palliative care available to them and it might be picking up a phone, getting some advice. Or if it's a really desperate situation, the patient might have a specialist in palliative care visit them at home or in hospital.

In rural and remote areas, it is a challenge, as with all healthcare services... You would never be able to set up palliative care specialist services in every rural and remote area... However, with developments in telehealth, people in the remote areas should be able to link in to a city-based palliative care service. And if there was somebody in a rural and remote area requesting voluntary assisted dying, there would be so many of my colleagues in palliative care just ready to help that person with palliative care advice, through telehealth... And with the improvement in telehealth techniques, and links between services, that expert backup should be available to patients needing palliative care.

The proposed Australian laws are not intended to replace palliative care. They simply add one more end-of-life option alongside palliative care; when even the most heroic efforts of doctors and nurses can no longer help; and when patients, exhausted by both their illness and its treatment, have suffered enough. (See page 40, VAD and palliative care go together.)

“Fears of loss of reputation, trust and funding are quite unfounded. Palliative care stands to gain in recognition and support through the introduction of VAD in Australia.”

**PROF IAN MADDOCKS,
THE ‘FATHER’ OF AUSTRALIAN PALLIATIVE CARE**

Won't VAD lead to doctor shopping?

An argument sometimes raised against VAD is that a person seeking an assisted death may go 'doctor shopping' until they find one who agrees to help.

The fundamental eligibility requirement for a person to access VAD in Australia is that they have a terminal illness with a prescribed period of time left to live. 'Doctor shopping' implies that someone who does not have an eligible diagnosis, and who wants an assisted death, will keep searching for a doctor who will give them the 'correct' diagnosis.

Australian VAD laws, including the NSW bill, safeguard against this kind of 'doctor shopping' and the prospect of multiple VAD applications. The creation of an independent Review Board is mandated to oversee every step of the process to ensure that multiple applications from the same person are flagged. If the board is concerned that the person may be ineligible, the process immediately ends.

It is, of course, everybody's right to seek a second (or third) medical opinion. However, as Victoria has shown, the ability to 'doctor shop' for the 'right' terminal diagnosis is also made impossible by the two realities:

1. There are only a limited number of doctors who are trained to assess for VAD. After the first 24 months of the law's operation, of the 265 registered oncologists, only 41 had done the training, and of 224 neurologists, only 11.
2. No matter how many doctors you see for VAD, the bar never lowers: You must meet the eligibility criteria or you will not be granted the legal right to an assisted death.

While this forecast 'doctor shopping to get around the eligibility criteria' does not happen, evidence from Victoria shows that eligible terminally ill people are sometimes forced into another, more pernicious, form of doctor shopping.

Because medical practitioners can conscientiously object to being involved in VAD, finding a doctor willing to participate is not always straightforward – as 36-year-old Robbie Caliste discovered.

Suffering intolerably in the final stages of motor neurone disease (MND), Robbie approached his family GP to be his co-ordinating doctor. After initially agreeing, several weeks later she told Robbie she could not proceed, citing conscientious objection. Robbie's father Jean said:

It felt like the rug had been pulled out from under us because we had to start the process all over again, to find a doctor willing to be involved. – Robbie's father, Jean Caliste

Dr Kristin Cornell's 74-year-old father Allan, also dying of MND, sought VAD. The law says that he not only had to be found eligible by two doctors, one a specialist in his disease, but that his prognosis of 12 months or less to live had to be confirmed by a second specialist.

Based in rural Victoria, he approached two neurologists to confirm his prognosis. Both declined. For someone nearing the end of their life, and in great pain and distress, the refusal – and the additional delays it created – were devastating.

I reckon that's about the second time I'd ever seen him cry – Dr Kristin Cornell

For 75-year-old Helen Jebb, again in the end stages of MND, the search for that second, qualified neurologist meant it took her almost six months to complete the VAD process.

That was the hardest, the most time-consuming part of all. Helen's doctor wrote numerous letters and made numerous phone calls to, I don't know, it seemed like 30 neurologists – but nobody would do it, and Helen's doctor said: 'I think this is going to be a race between us getting the approval for the VAD and you dying.' – Helen's husband, Reg Jebb

Can we trust doctors to do the right thing?

Every day we trust doctors to perform procedures and provide medications that have the potential to end lives. We trust doctors to act well, even in such unregulated areas of end-of-life care as terminal sedation. It is difficult to understand the argument that providing doctors with *more* regulation will lead to them being *less* trustworthy.

A doctor's mission statement doesn't change under VAD law. Doctors are asked to act as they ordinarily do – diagnose, prescribe and care for their patients. Remember, too, figures from Victoria show that around one in three patients prescribed VAD medication never use it. Having been offered the option, they elect not to take it. Crucially, it is the person who decides – not their doctor.

"It's really hard on top of busy work [for doctors] to do this. There's a great commitment to the family. And the bureaucratic form filling: If you say to doctors, would you like to do more form filling? none of them put their hand up. So just being involved in it is complex and is work. No one's in this for the money. It's a big commitment to do it."

A/PROF CHARLIE CORKE, INTENSIVIST, MEMBER OF VICTORIA'S VAD REVIEW BOARD²³

"I think that through this role I've met some of the most extraordinary doctors in Victoria. And I say that with a great genuineness. These doctors, what they do for their patients has been amazing. ... I've always had a respect, obviously, but my respect for doctors is even huger through this."

SUSAN, VICTORIAN VAD CARE NAVIGATOR

Why is VAD not shown as the cause of death on death certificates?

When somebody dying of cancer chooses to hasten death by refusing further treatment, food and fluids, the death certificate shows they died of cancer. When a terminal patient dies as a result of life support being turned off, the death certificate does not show 'life support turned off' as the cause of death. When somebody with kidney failure chooses to stop dialysis, it is their kidney failure, not their decision to stop dialysis, that is listed on their death certificate.

The same principle applies with assisted dying.

IT WOULD BE INCONSISTENT TO INCLUDE VOLUNTARY ASSISTED DYING ON A DEATH CERTIFICATE WHEN OTHER INTERVENTIONS ARE NOT RECORDED²⁶

THE VICTORIAN MINISTERIAL ADVISORY PANEL

Death certificates are public documents, used for a range of purposes. To make publicly available someone's choice of VAD as a medical treatment would threaten a person's privacy, as well as that of their family and the medical practitioners involved.

National Disability Services, in their submission to the WA Ministerial Expert Panel, explained it this way:

At the centre of the discussion is the balance between privacy and confidentiality of the person and the need to collect information about voluntary assisted dying. In some communities there may be significant impact on extended family of a person who has died through accessing voluntary assisted dying.²⁷

The panel also received feedback that raised concerns about potential stigma if third parties (such as funeral directors) who have links to the person and their family or community were aware that a death had occurred through voluntary assisted dying:

The certification of death should match that concerning death itself; sanctity and respect.

VAD death certification should be as respectful and confidential as possible to ensure it cannot be used for any religious or political agenda of any faith or secular group. – Submission by the Anglican Social Responsibilities Commission²⁸

NSW: A HYBRID APPROACH

Every state's VAD law has so far ruled out showing VAD as a cause of death on a publicly available death certificate.

However, there are other stages of death registration where **it is possible to maintain an individual's privacy while also recording deaths by VAD for statistical purposes.** Both Victoria and the proposed legislation in NSW opt for this hybrid approach.

The NSW bill says the 'notification of death certificate' that the doctor prepares for the Registry will include voluntary assisted dying as a cause of death. This certificate is not public but is accessible for statistical purposes by the Australian Bureau of Statistics and the World Health Organization. This requirement follows a recommendation from doctors.

Similarly, Victoria's law requires a medical practitioner to notify the Registrar if a person has a VAD permit, whether the person accessed VAD and the terminal illness that made them eligible.

No Australian state law – nor NSW's proposed bill – requires public death certificates, as issued by their respective Registries, to include any reference to VAD. In fact, it is prohibited in every state except Tasmania, where the law is silent on the issue but the University of Tasmania Expert Panel observed 'it appears to be generally accepted that the cause of death is the underlying terminal illness, and should be recorded as such.'²⁹

Is it true people are choosing VAD because they feel a burden?

It is true that one of the many ways in which a dying person can suffer towards the end of life is by feeling like they are a burden on those they love. It is not true to say that this is the reason they are given the legal right to end their suffering through voluntary assisted dying.

NO ONE IN OREGON CHOSE AN ASSISTED DEATH BECAUSE THEY FEARED 'BEING A BURDEN'

The source of this often-repeated claim – that people are choosing to die 'because they feel like a burden' – is Oregon, which surveys people about their reasons for opting for voluntary assisted dying. People are given a multiple-choice list of end-of-life concerns they may be facing as they die. These include: loss of autonomy, loss of dignity, loss of enjoyment in life, loss of bodily functions, inadequate pain control and feeling like a burden. They can choose as many of these options as apply.

When Oregon data is examined in context,³⁰ being a burden is not the only – or even the main – motivating factor for choosing assistance to die. In fact, it is

well down the list, the chief reasons being loss of autonomy, dignity and enjoyment in life.

However, none of these factors are the reason these people have chosen and been given legal access to VAD. There is only one reason they are eligible: **they are dying.**

The diseases they are dying of – mostly cancer, but also congestive heart failure and neurological diseases such as motor neurone disease – can all be seen on the yearly reports published by the Oregon Department of Health.³¹

Since its inception in 1997, nobody – not a single person – in Oregon accessed voluntary assisted dying simply because they felt like a burden. They ticked 'being a burden' as just one of their end-of-life concerns **because they were dying.**

“The dying are witnesses to their family’s pain just as the family are witnesses to theirs.”

DR LIBBY SMALES, PALLIATIVE CARE PHYSICIAN

CHARACTERISTICS	2020		TOTAL	
	(N=245)		(N=1,905)	
END OF LIFE CONCERNS				
Less able to engage in activities making life enjoyable (%)	231	(94.3)	1,713	(89.9)
Losing autonomy (%)	228	(93.1)	1,725	(90.6)
Loss of dignity (%)	176	(71.8)	1,308	(73.6)
Burden on family, friends/caregivers (%)	130	(53.1)	905	(47.5)
Losing control of bodily functions (%)	92	(37.6)	822	(43.1)
Inadequate pain control, or concern about it (%)	80	(32.7)	522	(27.4)
Financial implications of treatment (%)	15	(6.1)	86	(4.5)

SOURCE: OREGON DEATH WITH DIGNITY ACT, 2020 DATA SUMMARY ³²

Why a 12-month timeframe for people with a neurological disease?

Defining terminal illness by timeframes

Medical and health practitioners commonly use the word 'terminal' to describe a situation when an illness or disease is expected to result in a foreseeable or imminent death.

Foundational to all Australian VAD laws is the requirement that a person must have a terminal illness to be eligible to use the law – and this is measured using a 'timeframe to expected death'.

A timeframe to death is not a new concept. It is referenced extensively in Australian palliative care, often supported by the Surprise Question (a screening tool used to identify people nearing the end of life: "Would you be surprised if your patient was still alive in 12 months time?")

As the Queensland Law Reform Commission explained:

A specific timeframe until expected death makes it clear that voluntary assisted dying is an option only for those who are at the end of life. It maintains the principle that voluntary assisted dying is not a choice between life and death but a choice for those who are dying to exercise some control over the timing and manner of their death. A specific timeframe gives clear guidance to the community and the health profession about who is eligible.³³

Four Australian states have opted for a timeframe of six months or less until death, or 12 months for neurological conditions. This approach is also proposed in NSW.

It is favoured for the clear guidance it provides to medical practitioners and its broad consistency with wider medical practice in Australia; existing end-of-life and palliative care policy documents use this approach, such as the National Consensus Statement: Essential Elements for Safe High-Quality End of Life Care.³⁴

The exception is Queensland, where timeframe to death is 12 months for all conditions.

Why 12 months for neurological diseases?

The other states extend VAD eligibility to a 12-month timeframe for neurological diseases, such as motor neurone disease, to acknowledge the different clinical trajectory of non-malignant conditions. The need was best explained by the Victorian Panel:

[For neurological disease]...the average life expectancy from disease onset is 2.5 years. As people with Motor Neurone Disease lose their fine motor skills relatively early in the disease's trajectory they may also lose the physical ability to self-administer the lethal dose of medication. It is important that people with diseases, illnesses and medical conditions that affect fine motor function are given sufficient time to consider all of their options, and a 12 month timeframe will give them this opportunity.³⁵

Are time frames necessary?

There are many arguments to do away with time frames altogether, especially for people with degenerative chronic or neurological conditions.

Often the progression of these diseases is unpredictable; decline can happen swiftly and with devastating consequences, even in those patients whose death was not predicted for many months. Sometimes, too, the suffering of an incurable and irreversible disease is greatest in those who are not immediately dying: rather, they are condemned to even greater suffering over a longer period.

IT IS THE INTOLERABLE QUALITY OF LIFE PRECEDING DEATH, NOT THE COUNT OF DAYS, THAT IS KEY

For example, a person with advanced multiple sclerosis, or with motor neurone disease, may face many years of extreme pain, loss of autonomy, indignity and mental anguish.

Indeed, initially parliamentary committees in Victoria and WA did not recommend specific timeframes for the assessment of terminal illness (although expert panels later did recommend 12 months). Tasmania's law was introduced to the Upper House without a specific timeframe to death. They considered doctors well-equipped to assess when patients would be at the end of life, and that arbitrary time limits would be too restrictive for the sometimes volatile progressions of terminal disease.

The longer 12-month timeframe legislated in Queensland offers maximum palliative value; Victoria's experience shows almost a third of people found eligible for VAD die before the process can be completed. A blanket 12 months offers people the opportunity to get their medical choices in order earlier, lessening anxiety that a sudden, or cascading, deterioration in their condition will affect their ability to act.

Ironically, in allowing people a humane way in which to control their circumstances, many will choose to live longer, knowing they have an option should the worst happen. They can plan to farewell those they love and not leave behind the scars of an ugly suicide.

Lawrie Daniel's last letter to his family illustrates the extent of the suffering experienced by people with a progressive neurological disease who see no good option but to take matters into their own hands.

Lawrie, who had advanced multiple sclerosis, died alone in September 2016, without the opportunity to say goodbye to his family. He wrote:

If we had a compassionate Voluntary Euthanasia process in this country, none of this would have to happen the way that it has. I hope you can forgive me, and that you and the children won't see this as selfish, but as self-care, and self-compassion in a country where I had no alternative.

Scan or tap the QR code to watch a reading of Lawrie's Last Letter in full.



Why is there a 5-day waiting period between first and last request?

All Australian VAD laws have a 'cooling-off' period inbuilt. Victoria, WA and Queensland require nine days between a person's first and last requests (excluding the day on which the first request is made); Tasmania requires no less than four days.

The NSW bill proposes at least five days between first and last requests. While longer than Tasmania, it is shorter than in other states. This is because in NSW applicants must acquire a VAD permit as part of the process, a requirement that does not feature in the Queensland or WA Acts. This permit process takes several days to complete.

A waiting period recognises the need to guard against impulsive decisions by people experiencing extreme physical and emotional pain. It is intended to ensure they give VAD proper consideration and is consistent with the law's core principle, that any request for VAD must be voluntary and enduring. And, of course, at every step of the process the person is reminded that they can withdraw at any time. (See page 36, How can we be confident they are not being coerced.)

The independent Queensland Law Reform Commission wrote in their report:

To some extent the operation of the request and assessment process will naturally create a period of time over which a person can consider (and must sustain) their decision. However, particularly as voluntary assisted dying becomes an established end of life option and access increases, this may not always be the case. The inclusion of a minimum required period of time between the first and final requests ensures that there will be a minimum period of time for consideration and reflection.³⁶

All states, including the bill in NSW, have specified that if a person is likely to die before the waiting period has elapsed then the time between first and last requests can be shortened. WA, Queensland, and the NSW bill, also allow an application to be expedited if the person

is at risk of imminently losing capacity. Support for this provision was shown in a number of submissions to the WA Ministerial Expert Panel:³⁷

... perhaps with the ability to reduce times if the patient is undergoing excruciating pain that cannot be relieved, or death is imminent within that period. – Submission by the Anglican Social Responsibilities Commission

Bethesda is of the view that it is reasonable to waive the waiting period if, in the opinion of two medical practitioners, the person will die before the waiting period has elapsed (as in Victoria). – Submission by Bethesda Health Care

Even though the VAD process can be expedited under certain circumstances, it cannot be completed in less than two days. Victoria's Ministerial Advisory Panel put it like this:

The requirement that a final verbal request cannot be made on the same day that the second independent assessment is completed should never be waived. The requirement ensures that, no matter what the circumstances, a person cannot rush through the voluntary assisted dying process.³⁸

KATIE HARLEY'S FATHER, PHIL, DIED AGED 70 OF METASTATIC BLADDER CANCER AND CHOSE VAD THROUGH PRACTITIONER ADMINISTRATION.

"10 days for someone who is in agony with every breath that they take... it's a long time." KATIE HARLEY

Scan or tap the QR code to hear how the time between first and last requests was shortened in episode 3 of the Better Off Dead podcast, 'Lucky Phil.'



SCAN ME

What is the difference between VAD and suicide?

The distinction between suicide and a rational decision to end inevitable suffering was clearly understood by New York's chief medical examiner, Charles Hirsch, when investigating the deaths of office workers who jumped from the Twin Towers on 9/11.

Faced with a terrible choice – a slow, agonising death by fire, or a quick death by jumping – many New Yorkers chose to jump. Seeing this as a rational choice to avoid needless suffering, Hirsch refused to classify their deaths as 'suicides'.³⁹

Voluntary assisted dying is not a choice between life and death. It is the choice of a terminally ill person about the manner and timing of their death (which is imminent and inevitable), and the suffering that must be endured.

This difference was underlined by the WA parliamentary committee:

*It is important not to conflate suicide with assisted dying. It is possible to distinguish temporary suicidal ideation from an enduring, considered and rational decision to end one's life in the face of unbearable suffering.*⁴⁰

This was echoed by the independent Queensland Law Reform Commission's report earlier this year:

*Health practitioners who follow an exacting process to assist a dying person to choose the timing of their death should not be characterised as assisting suicide.*⁴¹

Peak suicide prevention body, Lifeline warns of the dangers of linking assisted dying and suicide:

Words can cause harm. Any linkage between euthanasia and suicide has the potential to cause harm.

*We recommend that any public debate surrounding euthanasia refrains from making the link to suicide, as this can provoke suicidal ideation.*⁴²

Multiple Australian parliamentary inquiries into end-of-life care in the last five years have revealed a disturbingly high incidence of suicides of the terminally, and chronically, ill.

National Coronial Information System (NCIS) data shows in NSW in 2019 there were 101 suicides by people over the age of 40 with terminal or debilitating illnesses – or who had experienced a significant decline in physical health prior to their death. These account for more than 20% of intentional self-harm deaths in that age bracket in that year.

In Queensland, seven people with terminal and debilitating illnesses took their own lives every month in 2016 and 2017.

ONE IN 10 SUICIDES IS BY A PERSON WITH A TERMINAL OR DEBILITATING ILLNESS⁴³

During WA's parliamentary inquiry, the State Coroner presented evidence that one in ten suicides in WA in any year are by people suffering with terminal or debilitating chronic diseases.⁴⁴

Prior to the introduction of Victoria's VAD law, State Coroner John Olle estimated a similar number of suicides each year – around 10% – were by people with chronic, debilitating or terminal illnesses. When asked if palliative care and support services might have reduced these 240 suicides between 2009-13, he responded:

The people we are talking about ... have made an absolute clear decision. They are determined.

The only assistance that could be offered is to meet their wishes, not to prolong their life.⁴⁵

Opponents of VAD have claimed that VAD increases suicide rates. But since Victoria's law was introduced, the state's suicide rate has remained steady: In 2020 there were actually 20 fewer suicides reported than in the previous year.

Although there is not yet research establishing a conclusive link between VAD laws and a reduction in suicide, from interviews conducted by Go Gentle with families of some of the 331 terminally ill Victorians who used VAD to end their lives between 2019-21, we know of at least two people who were strongly considering suicide if VAD had not been available.

One was 82-year-old Margaret Hogg, who was dying of the rare, neurodegenerative disease, Cortico-basal syndrome. Her daughter, Lisa, told us:

She said, 'Oh, I've worked out how I'm going to kill myself.' And my sister just said, 'What are you going to do?' And she said, 'I've got some scissors,' and she said, 'I'm going to just keep cutting until I die.' And I think it was at that point, my sister... it really drove home to her how desperate Mum's situation was.

Another was 74-year-old Allan Cornell who, dying of motor neurone disease and losing control of his body, told his daughter:

I went through the dilemma of blowing my brains out, but I don't own a shotgun or a rifle. Okay, the ute's still there. 120k into a very sturdy tree. It's very common. That's messy. It's messy on the people who find you. It's a very badly thought-out plan. It's desperation at its worst. It's got to be soon, otherwise you won't be physically capable of doing anything.

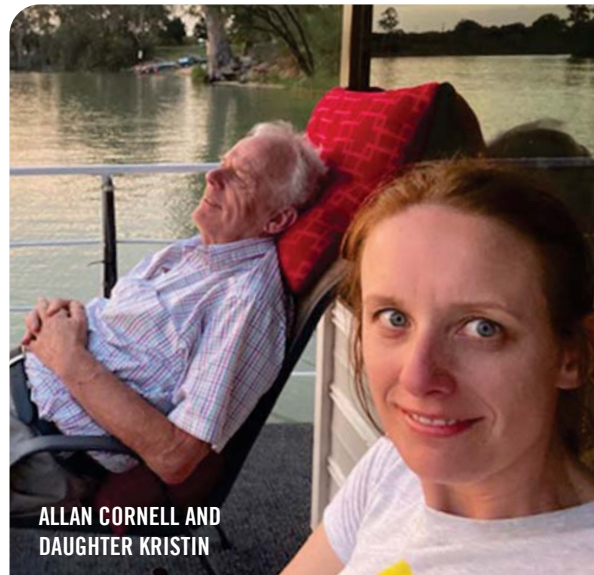
As the WA Parliamentary Committee said:

It is impossible to quantify the number of people who attempt suicide and fail. However, there is evidence that many do and are left further debilitated.⁴⁶

Providing terminally ill people, who are suffering without relief, a safe, reliable way to end their suffering

through VAD offers them a better choice than ending their lives prematurely, while they still have the physical capability, or risking a botched attempt that leaves them in a worse state than before.

VAD also prevents significant harm to families, carers and first responders, who are often witnesses to very distressing scenes.



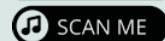
ALLAN CORNELL AND
DAUGHTER KRISTIN

ALLAN CORNELL'S STORY

"He felt very looked after and he knew he was at home and he knew we were with him. And he was very relieved. He was at peace. The struggles that he'd been feeling I think were gone."

KRISTIN CORNELL

Scan or tap the QR code to listen to Allan Cornell speak on Episode 13 of the Better Off Dead podcast, 'Unintended Consequences'.



Is VAD medication reliable?

VAD medication in Australia is extraordinarily safe and reliable.

In Victoria, the coordinating practitioner writes the prescription under the supervision of the Statewide Pharmacy Service. This pharmaceutical team is responsible for preparing and delivering all VAD medications in the state. They report a 100% success rate and no cases of significant complications with the medications in the program's first 24 months of operation, which has seen 331 people use the medication to end their lives.

During the scheme's 18-month implementation, the Victorian government appointed Professor Michael Dooley as Chief of the Statewide Pharmacy Service and tasked him with building the most effective system of prescribing and dispensing VAD medications.

As one of Australia's leading experts in clinical pharmacology, Professor Dooley has an extensive background in oncology and palliative care and runs a research centre into medicine safety at Monash University. He says the VAD system is working as intended:

There is a rigorous protocol. It tells you exactly what medication can be used, both orally and intravenously, gleaned from research and overseas experience.

Of all the patients that we've treated to date, there haven't been any... that have taken the medication and not passed away.

Professor Dooley said after swallowing the medications the majority of patients fell unconscious after a few minutes and had stopped breathing within half an hour.

The most common words he has heard used by families to describe their loved ones' deaths were "beautiful", "peaceful" and "dignified". (See page 45, Saying farewell: I choose not to suffer.)

"There have been no instances where the medications haven't worked. No instances where the medications have gone missing. And there hasn't been one case where the patient wasn't suffering intolerably and wasn't justified in seeking this course of actions."

**PROFESSOR MICHAEL DOOLEY,
VICTORIAN STATEWIDE PHARMACIST⁴⁷**

".... this isn't radioactive, it's not Ebola. This is... a medication that's incredibly unpalatable. It's in a locked box. There's a lot of medications in people's cupboards at home that you get on the PBS in a packet of 60 or a packet of 30. That if you take that whole packet, it will result in you dying. So ... it's interesting that people get very concerned about this particular medication."

**PROFESSOR MICHAEL DOOLEY,
VICTORIAN STATEWIDE PHARMACIST⁴⁸**

Shouldn't there be a mandatory psychiatric examination?

That there should be a mandatory psychiatric examination built into the VAD application process has been debated – and rejected – by all five parliaments that have passed VAD laws.

In summary, the reasons against mandatory psychiatric examination were as follows:

- The assumption of mental capacity until proven otherwise is a well-established legal principle, enshrined in Australian law and applying to all medical decision-making. A person's mental capacity cannot be questioned just because others do not support their choices or those choices have life-ending consequences.
- A compulsory psychiatric assessment will impose an unreasonable burden on some people, particularly in remote rural areas, with limited access to mental health specialists. It will also prolong the waiting time before eligibility is granted, which may prolong a terminally ill person's suffering or lead to ineligibility, due to onset of unconsciousness or mental impairment.
- Globally, no other VAD law requires compulsory psychiatric assessment. Most existing legislation requires a psychiatric assessment only where there is doubt about mental capacity or possible undue influence over a person's decision.
- Psychiatrists are not always the most appropriate specialist to assess capacity – geriatricians, psycho-geriatricians, neurologists, neuropsychologists, psycho-oncologists, psychologists, GPs and palliative care clinicians could all make capacity assessments. Legislation should not limit the types of referrals that can be made by an assessing medical practitioner.

Advice given in 2017 to Victorian MPs by two of Victoria's leading psychiatrists, Professor David Copolov and Associate Professor Steve Ellen, explained why safeguards contained in VAD legislation are adequate to address the question of mental competency:

Depression occurs in approximately 20% of patients in palliative care settings.

The majority of people with depression retain decision-making capacity; in fact, thousands of medical decisions requiring informed consent and capacity are made every day in Australia by people with depression. In psychiatric settings, people with depression (and other psychiatric illnesses) are assessed for capacity for many types of decisions that have major implications for their health and life.

The process for assessing capacity is set out in the Mental Health Act and the Medical Treatment Act and in the Bill. In summary, the person must understand the decision they are making, be able to weigh the pros and cons, and be able to communicate their decision.

In cases where the clinicians involved with a person requesting VAD have doubt about the decision-making capacity of a person, then an expert opinion should be sought from a medical specialist – this is standard practice in routine clinical care.

If the person fails to fulfil any one of the criteria relating to capacity – then they are not competent to make the decision. Experts are well able to assess a person's views and opinions, both longstanding and recent, and weigh the impact of the capacities. Sometimes information is sought from third parties who have known the person from before they were unwell. If in doubt, a second opinion is sought.

This legislation will in fact improve our capacity to detect mental illness in the terminally ill. Clinicians will be more vigilant in determining if it is present and, if detected, patients will be referred for psychiatric assessment and, if appropriate, care.

In summary, the processes and safeguards in the VAD legislation, combined with routine clinical care currently in practice in Victoria, will ensure that people requesting VAD will be assessed for their capacity, and that VAD will not be available to people who fail the capacity test.⁴⁹ (See page 38, How can we be sure they are mentally competent?)

Why a person is assessed on suffering and not just pain?

Suffering is an intensely personal experience and is not confined to physical experience or pain. People suffering life-limiting illnesses experience symptoms that are challenging to assess, treat and manage – even with the best palliative care. This is widely acknowledged, including by Palliative Care Australia and the Australian Medical Association.

While Australia's palliative care is highly regarded, it can never be completely effective due to intractable symptoms which arise from, for example:

- Cancer invasion of nerve-rich areas such as the abdominal cavity, chest cavity, spine, pelvis, or throat that leads to pain and, if in the pelvis, possible incontinence of urine and faeces. Cancer growth can also obstruct swallowing and the intestine, causing vomiting and, ultimately, starvation
- Paralyzing diseases of nerves supplying the chest and throat muscles that cause gasping or choking to death (such as motor neurone disease)
- Mesothelioma (an incurable asbestosis-related disease), which produces severe chest pain, often causing feelings of suffocation
- Difficult-to-treat neuralgia that causes electric shock sensations, with stabbing, agonising and jolting pain.

This range of symptoms is indicative, not exhaustive, and reveals that suffering is not confined to the final stage of a terminal illness. (See page 40, VAD and palliative care go together.)

If you've had an accident and a doctor wants to find out how much something is hurting, they must *ask* you. Only you, the patient, can determine your level of pain and whether it is tolerable. However, under Australia's VAD laws:

- Two doctors also have to agree that what you say is intolerable suffering matches their reasonable expectation, based on your medical history and symptoms

- Since you must have a terminal disease to access VAD, it is highly likely that the first doctor you consult has already been treating you for that disease, knows your medical history and disease's trajectory, and is well-placed to consider a claim of intolerable suffering
- Any doctor who receives a request for VAD, even if they have not been treating you, will consult your medical records. Proof is needed – because all records of a lawfully approved VAD request will go to the VAD Review Board for examination – that you have the disease you say you have and you are suffering intolerably
- Both independent doctors are also required to discuss all treatment options with you, to see if there are other ways to address your suffering which may be more effective, or have not been explored.

JEAN AND MICHELLE CALISTE'S SON ROBBIE WAS ONE OF THE YOUNGEST VICTORIANS TO DIE THROUGH VAD

"He didn't want motor neurone disease to win ... He didn't want to be literally that prisoner in the body and looking at you with his eyes. It had done enough damage to him and he knew what the outcome was going to be."

JEAN AND MICHELLE CALISTE

For a greater insight into how suffering at the end of life is about more than pain, listen to Episode 1 of the Better Off Dead podcast 'Belly of the Beast.'



How the Victorian VAD law works

The case study of Kerry Robertson

The following account was written after an extensive interview by Go Gentle Australia with Kerry Robertson's daughters.⁵⁰ A version can also be read in *The Age*.⁵¹

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.

Timeline of events

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.



PART 3

What we've learnt from Victoria

Introduction

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."⁵²

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, more than two 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; 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 Victoria's VAD Review Board's reports here at the Safer Care Victoria website: bettersafercare.vic.gov.au/about-us/vadrb



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 mils 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, 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**

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, 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, 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 in Victoria – and how they still do in NSW, today.

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 two 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.

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.

58% OF THOSE WHO RECEIVED MEDICATION DIED THROUGH SELF-ADMINISTRATION, 10% BY PRACTITIONER ADMINISTRATION.

32% OF THOSE WHO RECEIVED MEDICATION DIED WITHOUT USING IT.

83% HAD 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, Chair of Victoria's VAD Review Board**

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**

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 (COPD). Died March 2021**

Hear Ron Poole, Fiona McClure, and Peter Jones, three Victorians from very different backgrounds, explain why they chose to pursue VAD in Episode 5 of the Better Off Dead podcast, '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**

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**

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, 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 FINAL RECORDING OF THE BETTER OF DEAD PODCAST

**“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, 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, Episode 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**

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 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, Chair of Victoria's VAD Review Board**



“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 PRACTITIONER, ROYAL MELBOURNE HOSPITAL

A person seeking VAD has to be able to demonstrate competency 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, listen to Episode 10 of the Better Off Dead podcast 'We, Who Walk Towards Death.'



SCAN ME

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

234 MEDICAL PRACTITIONERS HAVE TRAINED AND ARE REGISTERED TO ASSESS FOR VAD

147 ARE GPS. 41 ONCOLOGISTS. 11 SPECIALISTS IN NEUROLOGY. AND 5 SPECIALISTS IN PALLIATIVE MEDICINE

OF THOSE, 185 HAVE BEEN INVOLVED IN ONE OR MORE VAD CASE

To learn more, listen to Episode 4 of the Better Off Dead podcast '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, 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, Episode 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**

A LETTER WRITTEN BY PHIL FERRAROTTO, 70, WHO WAS DYING OF METASTATIC BLADDER CANCER, TO HIS DOCTOR CAMERON MCLAREN

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.

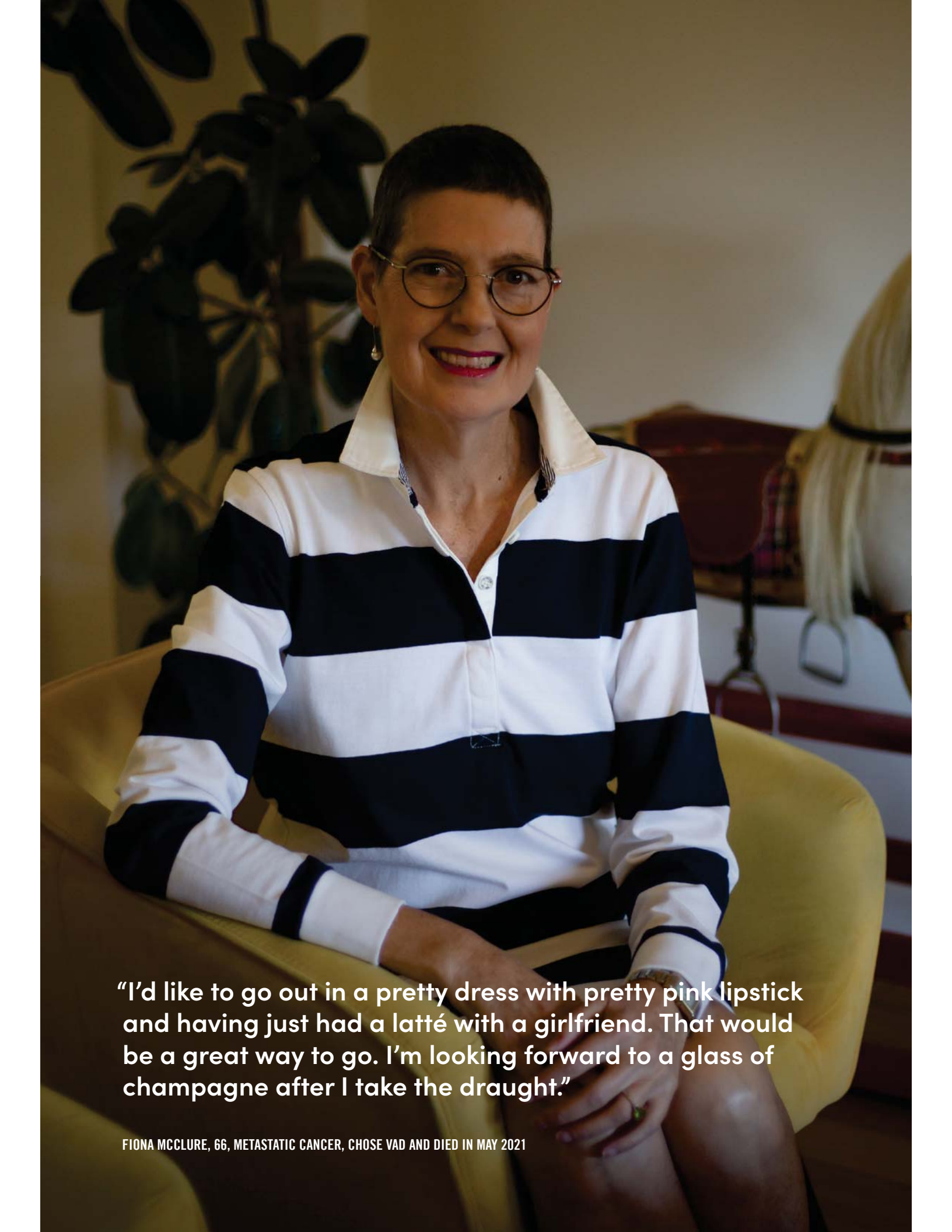
Best wishes for your future, mate.

– Phil.



For the full story, scan the QR code to listen to Episode 3 of the Better Off Dead podcast 'Lucky Phil.'





"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

PART 4

Four questions for legislators

Does this law make end-of-life practices in NSW safer?

Parliamentary inquiries into end-of life care across Australia have accepted evidence demonstrating that assisted dying already occurs, despite being unlawful.

The Victorian Cross-Party Parliamentary Inquiry into End-of-Life Choices (2016) found that:

Doctors practice unlawful assisted dying despite its prohibition and despite prospective liability for serious crimes.⁵³

In their submission to the Western Australian Joint Select Committee Inquiry into End-Of-Life- Choices (2018), Doctors for Assisted Dying Choice told the committee about:

... an anonymous survey of Australian medical practitioners [that] indicated that 35% of doctors have, at the request of their patient, provided medical treatments with the aim to hasten and shorten the duration of suffering for their patients. Because under the current law, these doctors could face criminal charges, these practices remain hidden and are unspoken.⁵⁴

These same inquiries also accepted research which examined doctors' intentions when administering pain-relieving medication, and whether the provision of this treatment always complied with the law.

Legally, an act done with an intention to relieve pain is lawful (even if death is foreseen), but the same act done with an intention to end life is not lawful.

Despite this, some doctors treating terminally ill patients intend to end suffering by ending life when they administer pain-relieving medication, and so will be acting unlawfully. Further, the palliative practice of 'terminal sedation' – where a patient is kept under deep continuous sedation to manage pain, while artificial nutrition and hydration is withdrawn or withheld ultimately leading to death – can give rise to legal ambiguity and has sometimes been equated to 'slow euthanasia'.

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

When I think back over the years when I've helped people at the end stage of life, there were 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

Two adverse consequences flow from the fact that unlawful practices occur.

The first is that as these practices are unlawful, they are unregulated. Regulation promotes good practice and, conversely, there are dangers inherent in unregulated practices, particularly where they lead to people's lives being ended. For example, which patients are acceptable for doctors to assist to die? What practices are acceptable to achieve this purpose? Are doctors covertly making quality of life assessments that result in a decision to end a person's life?

Legalisation and regulation of assisted dying allows for the creation of appropriate safeguards and oversight to ensure, for example, that a decision to end life is made only by a competent adult.

The second consequence of the existence of unlawful practices is that the ongoing occurrence of such practices in defiance of the law has the consequence of bringing the law into disrepute.

"The current laws are outdated and put patients and health practitioners at risk. Some doctors have acknowledged that people are being assisted to die right now. But this practice is hidden, unregulated and potentially unsafe. This bill provides a legal framework ensuring protections for the person and for health practitioners. No health practitioner who follows the requirements of the bill should be worried about being prosecuted."

ROGER COOK. WA HEALTH MINISTER 2019

Does this law protect religious freedom?

All Australian VAD laws, including the NSW bill, have, at their core, the right for medical professionals to conscientiously object to VAD, for any reason, without sanction or criticism.

This enshrines the freedom of all to act according to their conscience and beliefs.

This does not mean that a medical practitioner can entirely abandon a person seeking VAD. The NSW bill, like laws in WA, Tasmania and Queensland, requires a conscientiously objecting medical practitioner to refer a patient seeking information about VAD to services capable of supplying that information, such as the VAD Care Navigators, and to do so in a timely manner.

While the religious freedoms of individuals to conscientiously object are protected, the right of institutions to do the same are not absolute.

In the NSW bill, hospitals can refuse to participate in VAD but they must facilitate a person's transfer to another facility.

This is an important element of the bill. While an individual's right to conscientiously object is fundamental to a law whose first word is 'voluntary', the right of an institution to obstruct access to VAD is another matter.

Fundamentally, the NSW law says that the rights of the people for whom this law has been written – the terminally ill – must in no way be compromised by the moral objections of an institution. This is because people suffer, institutions do not.

While NSW hospitals will have a right to refuse participation in VAD, that will not be the case for retirement villages and residential aged care facilities.

These are often people's permanent residences and the law says they should not be denied access to legal medical treatments in their own home.

The NSW bill takes a more conservative approach than that of Queensland. While hospitals in Queensland can decide not to actively participate in VAD, if a person in their care seeking VAD cannot be safely transferred, they must allow external VAD doctors on site to treat people. The NSW bill does not contain this provision.

The Queensland law draws a line that the NSW bill does not – weighing up the competing harms of moral distress caused to an institution which conscientiously objects, against the actual harm done by forcing a terminally ill person to move, when doing so would cause them greater harm, or lead to them losing mental competency.

In that instance, Queensland's law seeks to protect the person suffering from that greater harm.

Both Queensland's law and the NSW bill seek to strike a difficult balance: Respecting the religious freedom of healthcare workers and institutions, while minimising the physical, emotional and psychological distress being inflicted on people at the end of their lives, and seeking VAD.

Does it make end-of-life practices in NSW more equitable?

Aspects of current NSW law in relation to end-of-life care are incoherent or illogical:

- Withdrawal or withholding of life-sustaining treatment that results in a person's death may be lawful, but the provision of a lethal dose intended to cause death is not
- Terminal sedation may be lawful, but can also be unlawful depending on the doctor's intention when giving the medication
- Suicide is legal, but assisting someone with suicide is illegal
- There is a lack of clarity about what is meant by 'assisting' someone to die
- Even in a clear case where a person has 'assisted' another to die, some individuals are prosecuted and jailed for providing that assistance, and others are not⁵⁵

The issue of health equity is not commonly raised as a consideration in respect of law reform to allow VAD.

However, as one critique of the legal status quo argued in respect of unequal access to a peaceful death:

*The current two-tier system – a chosen death and an end to pain outside the law for those with connections, and strong refusals for most other people – is one of the greatest scandals of contemporary practice.*⁵⁶

The Rule of Law requires that law must apply equally to all, but this is not the case in this field. Whereas some may be able to end their own life, another person's disability may prevent them from doing so.

Further, a person who is ill and relying on life-sustaining treatment to survive (such as a respirator) may lawfully ask for it to be turned off. Another person who is equally ill, but suffering from a different condition which does not require a respirator, cannot be assisted to die.

At present, there are some who access assisted death despite it being unlawful. Those people are generally able to do so because they possess some privilege. It may be privilege in terms of education, or it may be in relation to contacts and connections they have within the medical or veterinary professions. It may be the wherewithal and financial means to travel to an assisted dying clinic in Switzerland.

The operation of the law cannot be justified if a privileged few are able to receive assistance to die, but others cannot.

There is also the imbalance that currently exists in law between patients and doctors. Under existing law, doctors have total power to decide how much pain relief is given to a dying patient, at what speed and when.

Clive Deverall, founding president of Palliative Care WA, summed it up this way:

*And every day, in different settings, terminally ill patients – most with advanced malignancies and uncontrolled symptoms – are terminally sedated. Excellent. But that is the Lotto Life: the patient has to be lucky enough to find a doctor willing to help. And there is little or no transparency and a legal risk to the doctor and/or nurse.*⁵⁷

That doctors hold strong personal beliefs which may influence their treatment decisions is not at issue. It is not suggested that they are wrong to do so, or that they should be required to act otherwise. VAD laws rightly protect and respect a doctor's right to act according to her or his conscience in providing end-of-life care.

What is at issue is an existing law that enables doctors to impose those beliefs on dying people in their care. People who, in many cases, do not share those beliefs. People who are vulnerable; who are suffering as they die; and who make persistent and rational requests to end their suffering quickly.

Does this law meet community expectations?

Australians have long accepted that they should be free to make their own decisions about how they live and end their lives.

Consistent, reliable opinion polling over two decades reveals support for voluntary assisted dying to be in excess of 70%. In recent years, that support has risen to nearly 90%.⁵⁸ This is irrespective of variations in the questions and terminology used.

In the most recent polls, support has remained stable at between 82% and 88%, according to Newspoll (2012)⁵⁹, The Roy Morgan Snap Poll (2017), The West Australian (2018 and 2019),^{60, 61} and ABC's Vote Compass (2019).⁶²

Is VAD supported by the medical profession?

A significant number of doctors, nurses and allied health professionals support patient choice at the end of life.

This support extends across professional medical bodies. The Royal Australian College of General Practitioners, the Royal Australasian College of Physicians, the Australian and New Zealand College of Anaesthetists, the Australian Medical Students Association, Palliative Care Australia, and the Australian Nursing and Midwifery Federation, among others, have all either backed a VAD law, or adopted a neutral stance.

*It was all about patient choice regarding their end-of-life decisions. It's a very safe bill and it's been very well thought out. It's world class – Dr Tim Jackson, Chair, Tasmanian RACGP, describing his state's VAD law*⁶³

Although still formally in opposition, a 2016 survey, conducted by the Australian Medical Association (AMA) – which represents 30% of Australia's doctors – found

a majority of their members (51.6%) agreed assisted dying "can have a legitimate role in modern medical care".

However, even the AMA's opposition appears to be weakening. In September 2021, Dr Andrew Miller, the chair of the AMA's ethics committee, broadly endorsed the NSW VAD bill, saying it was "very similar" to the laws enacted in Victoria and Western Australia, where he lives.

*It has proven to be an effective compromise in my opinion in WA, and it has been introduced smoothly and without fuss... there is a good range of practitioners who are involved. The practitioners who don't want to be involved seem to be reassured. Basically [the NSW bill] looks to be consistent with the evolving national model.*⁶⁴

Previous AMA office holders have also changed their stance. Former Federal President, Professor Brain Owler, chaired the Ministerial Advisory Panel that helped frame Victoria's VAD law. In WA, two former state AMA presidents have publicly distanced themselves from the official AMA position, with one, Dr Scott Blackwell (also a member of WA's VAD Implementation Committee), declaring that he was disappointed with the AMA's opposition.

*[It is] unnecessary and probably unrepresentative of the body of people who call themselves AMA members, and certainly of the body of people who call themselves doctors in WA.*⁶⁵

**51.6% OF AMA MEMBERS
AGREE THAT 'EUTHANASIA
CAN FORM A LEGITIMATE
PART OF CARE'**⁶⁶

PART 5

How have other states departed from Victoria's VAD law, and why?

Several states have modified aspects of Victoria's landmark VAD law, reserving the right to adapt and improve upon legislation to suit their unique circumstances, including geography and population diversity.

In his comprehensive report setting out Queensland's proposed VAD bill, Justice Peter Applegarth, chair of the state's Law Reform Commission, articulated why a state should not simply adopt another state's law because it happened to be passed first:

... in a federation, states are 'laboratories of democracy' in which different policies can be enacted and tested in a state, as in a scientific experiment. If the policy is a failure, it does not affect any other state. If, however, the policy is a success, it might be expanded to another state. If improvements are made in that next state, they might be adopted in another.⁶⁷

Justice Applegarth went on to argue another basic principle: legislation should be clear and no more complex than it needs to be to achieve its purposes. Improvements in this regard were to be welcomed, he said.

Changes adopted by other states

Doctors permitted to initiate conversations about VAD with patients

Victoria's VAD law strictly prohibits health practitioners from initiating a discussion about voluntary assisted dying with their patients. Victorian MPs considered this an additional safeguard against doctors asserting undue influence over vulnerable patients.

However, other states have argued this 'gag' limitation prevents health practitioners from fulfilling their professional duty to tell people about all their end of

life options and prevents patients making properly informed decisions about their care.

Western Australia, Tasmania and Queensland all permit a medical practitioner to initiate a discussion about VAD with their patient, provided it is part of a wider discussion about the person's treatment and palliative care options.

Requirement to refer the person to a specialist in their disease or illness

The Victorian law requires that one of the two assessing doctors in the VAD process must be 'a specialist in the person's disease, illness or medical condition'.

All other states have reviewed this requirement and determined it to be an unnecessary barrier to a dying person's access to VAD. They have determined that doctors with years of clinical experience – and who have completed the mandatory VAD training – have sufficient knowledge and skill to carry out the VAD eligibility assessment. If doubts arise about a person's eligibility for VAD, doctors can seek the opinion of a specialist, including the person's own specialist care team, if necessary; a process that is consistent with good medical practice.

Practitioner administration

In Victoria, self-administration of the VAD medication is mandated as the default administration method. Parliament accepted that self-administration is another safeguard to ensure voluntary assisted dying is, in fact, voluntary. As such, practitioner administration is allowed only if the person is physically incapable of self-administering or digesting the voluntary assisted dying substance and separate permission must be sought.

In their laws, Western Australia, Tasmania and Queensland deviated from this approach, permitting practitioner administration in broader circumstances

and recognising that a person should be able to make an informed decision about the method of administration that best suits them.

In these states, practitioner administration is deemed acceptable if:

- the person is unable to self-administer the substance;
- the person has concerns about self-administering the substance;
- the person, in consultation with their doctor, deems practitioner administration is the most suitable option for them.

Because of their geographical size and remoteness, Western Australia and Queensland have also broadened the pool of practitioners permitted to administer VAD medication to include nurse practitioners when doctors are unavailable.

Requirements of RACFs and hospitals who conscientiously object

All Australian states rightly protect the rights of individuals to conscientiously object to participation in any, or all, aspects of VAD.

On the matter of 'institutional objection', VAD laws in Victoria, Western Australia and Tasmania, are largely silent. As a consequence, they are also silent on an objecting institution's responsibilities and duty of care to patients in their care who seek access to VAD.

However, evidence from Victoria and Western Australia, of terminally ill people being obstructed by institutions in their pursuit of VAD raised questions about whether or not the law should remain silent on this issue.

Subsequently, South Australia became the first state to explicitly entrench an absolute right to object to participation in VAD for faith-based hospitals. However, alongside this right to object is the requirement that the hospital should transfer patients to another facility to access VAD. The South Australian parliament did not extend the same absolute right to retirement homes and aged care facilities (RACFS), arguing these facilities were often people's permanent residences and no one should be denied legal medical treatments in their own home.

Queensland accepted and further clarified the South Australian position on hospitals, mandating that in the

rare circumstances where a patient could not be safely transferred, or if transfer would cause undue delay and prolonged suffering in accessing VAD, the hospital must allow independent doctors onto the premises to carry out the person's VAD wishes.

To hear the story of how terminally ill Victorian man, Colin M, was obstructed by the institution in which he lived from pursuing his legal right to VAD, listen to Episode 8 'The Good Samaritan.'



Requirement for individuals to refer people to other services

Individuals who conscientiously object to VAD in Victoria are not required to provide people with information about, or referrals to, other medical services. Parliament deemed this essential to ensure that no conscientiously objecting individual felt pressure, even indirectly, to be involved in any facet of VAD against their wishes.

Western Australia, Tasmania and Queensland have qualified this absolute right to opt out, requiring objecting individuals to refer people seeking information about VAD to services capable of supplying that information, such as the VAD Care Navigators, and to do so in a timely manner.

You can find a detailed description of the differences in VAD laws between Australian states here.



How Australian medical bodies have changed their views on VAD

IN **2017** ONLY
TWO ORGANISATIONS
 OPENLY SUPPORTED
 VOLUNTARY ASSISTED DYING.
FIFTEEN
 WERE OPPOSED

IN 2021, most organisations are either neutral or in support of a Voluntary Assisted Dying law.



Australian Nursing &
Midwifery Federation



AUSTRALIAN
PARAMEDICS
ASSOCIATION



AASW
Australian Association
of Social Workers



PalliativeCare
AUSTRALIA



NSW
NURSES &
MIDWIVES'
ASSOCIATION



WA Primary
Health Alliance
Better health, together



ANZCA
AUSTRALIAN AND NEW ZEALAND
COLLEGE OF ANAESTHETISTS



Public Health Association
AUSTRALIA

BY 2021

SIX ORGANISATIONS
SUPPORT VAD, AND

EIGHT ORGANISATIONS
ARE NEUTRAL

THREE ORGANISATIONS REMAIN AGAINST



Only the three organisations below remain against.

PART 6

Why facts matter

Ben White, Professor in the Australian Centre for Health Law Research at QUT, an independent researcher who has been working in this field for 18 years, has this to say about the assisted dying debate:

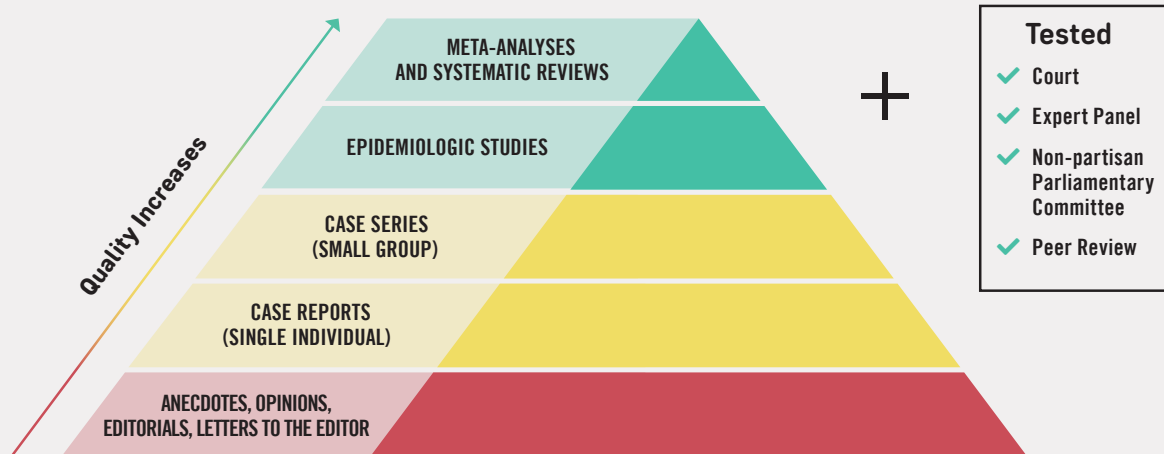
Voluntary assisted dying is a critical social issue. Both sides of the argument have a duty and responsibility to be transparent in their views and also to be clear about the evidence they are relying on. Where there is trustworthy, reliable evidence that sheds light on how voluntary assisted dying regimes work, it's absolutely critical that law makers, parliamentarians, parliamentary committees, politicians, media, and policy advisers must have

access to that, engage with that and understand how it can help make evidence-based law.

If you want to know whether the information is credible or not, a starting point would be to look at who the author is; and whether or not their work is peer reviewed, or systemically accountable. If it is a government department, for example, you might have confidence in the information that is there.

Similarly, there have now been several parliamentary committee reports in Australia. All are available online and detail the evidence about assisted dying here and overseas. These are trustworthy sources of information.

Higher up pyramid + tested = Greater reliability



SOURCE: NEWDEMOCRACY FOUNDATION⁶⁸

We all have an extraordinary responsibility in debates about voluntary assisted dying and should:

- Look carefully at the evidence at the top of the evidence pyramid;
- Keep in mind the vast experience of the clinicians and others, who have informed the writing of these laws;
- Remember for whom the law is intended – those who are dying and suffering, and who are seeking a choice about how much they need to suffer;
- Evaluate the bill as a whole and resist picking out individual provisions in isolation;
- Resist the temptation to 'pile on' ad hoc safeguards to already sound VAD laws, making them harder for terminally ill people to access, but no safer.

“Some evidence will be more reliable than others and there’s established ways to test this. Evidence which draws on a large body of peer reviewed [material]... We can have more confidence in evidence like that than that which might be a handful of cases which are anecdotally reported.”⁶⁹

BEN WHITE, PROFESSOR IN THE AUSTRALIAN CENTRE FOR HEALTH LAW RESEARCH AT QUT



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2. Nancy Elliott in Andrew Denton, "Better Off Dead: #1 The invasion of death", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/1-the-invasion-of-death> Transcript at Go Gentle Australia website – <https://www.gogentleaustralia.org.au/transcripts1>
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Five states have now passed VAD laws.



“We now need to consider issues of equity of access to health services. Not putting in place a voluntary assisted dying regime would deny... access to a health service which is becoming available to a majority of Australians.”

HEALTH MINISTER STEPHEN WADE DURING SOUTH AUSTRALIA'S PARLIAMENTARY DEBATE