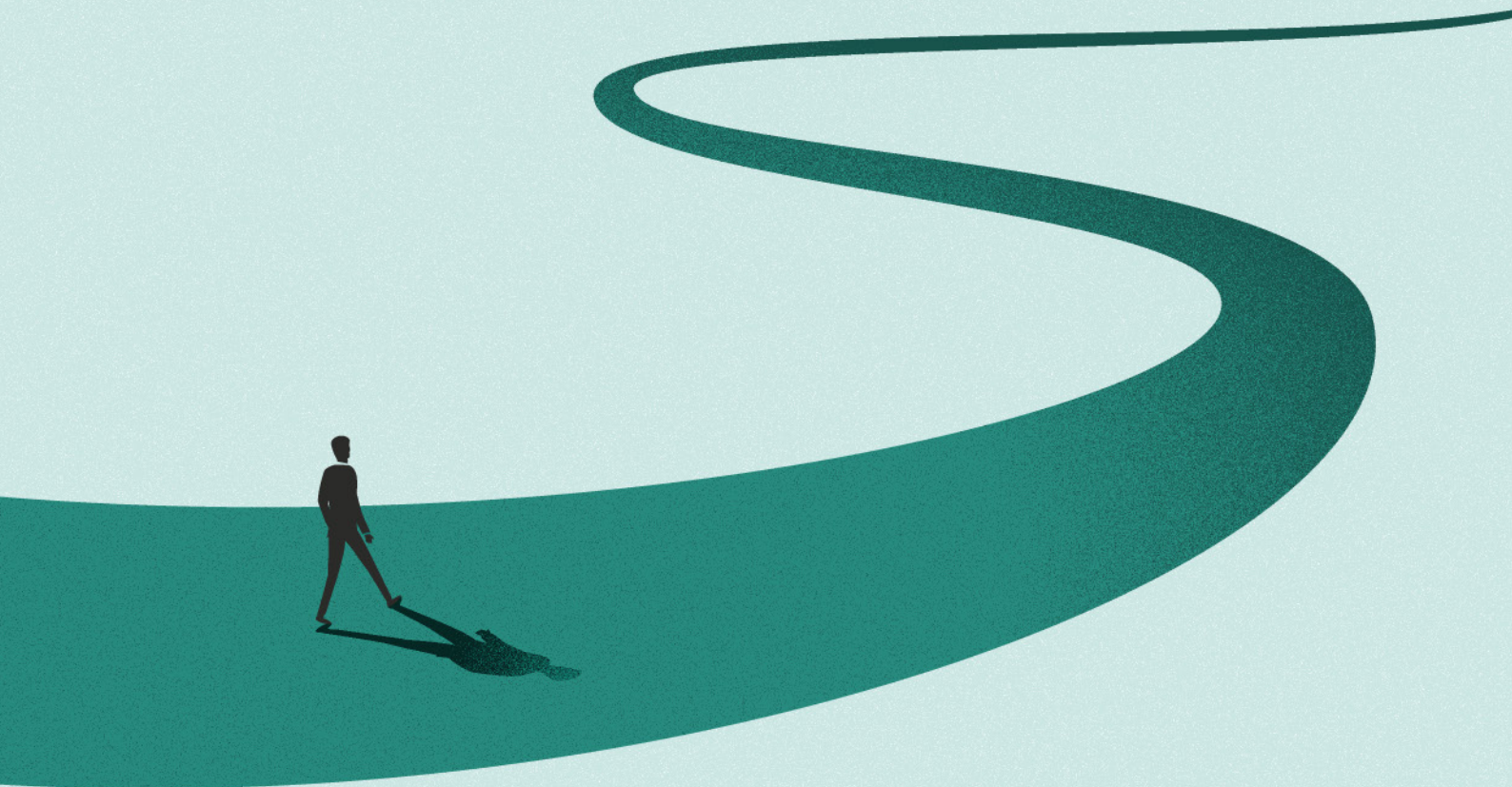


A Guide to the Debate on Voluntary Assisted Dying

IN AUSTRALIA



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Go Gentle Australia has been established to help relieve the distress, helplessness and suffering experienced by Australians with untreatable or terminal illnesses, their families and carers.

If you would like to learn more, visit us at **gogentleaustralia.org.au**



Go Gentle Australia is an expert advisory and health promotion charity founded by Andrew Denton to spark a national conversation about end-of-life choices, including voluntary assisted dying. Our focus is on promoting evidence that is based on established facts and peer-reviewed research.

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Introduction

The debate ahead Clock and bomb

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

Any proposed voluntary assisted dying bill in your state or territory is like a clock. A piece of legislation, with careful input from experts, including of 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 effectively and uncontroversially in Oregon since 1997, in numerous other jurisdictions in Europe and the US and, since June 2019, in Victoria.

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 these 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 did in the Victoria and Western Australia – will use every tactic they know to try and make you forget that it is a clock, and to 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 shows that the 'clock' works as it is meant to. They know that the doctors and nurses you have heard from, who've talked about the need for this law and the protections it provides, are hard to deny.

Faced with these realities, they have only one tactic. Use the parliamentary debate, which allows that the clock be pulled apart so that it can be examined, to 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 you are most likely familiar with, known as the 'Gish gallop'. Here's how Wikipedia describes it:

The Gish gallop is a technique used during debating that focuses on overwhelming an opponent with as many arguments as possible, without regard for accuracy or strength of the arguments.¹

They know this tactic works. It's part of a deliberate strategy used by opponents of VAD to defeat almost 50 pieces of legislation in Australia before Victoria's law finally passed. This strategy was spelled out to an international anti-euthanasia convention in Adelaide in 2015, by New Hampshire legislator, Nancy Elliott:

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 most crucial thing to keep in mind is this: Who is this law for and how does it work to help them, and them specifically, at the end-of-life? In other words;

Don't lose sight of the clock.

- Go Gentle Australia.

Part A | Some facts

Why VAD now? The unintended consequences of our existing laws

After years of inquiry, the respective Parliamentary Select Committees on End of Life Choices in Victoria, Western Australia and Queensland found that too many Australians are experiencing profound suffering as they die. Victoria's parliament, acting on their committee's recommendations, passed a Voluntary Assisted Dying Bill in 2017. Western Australia, after a bruising parliamentary debate, followed suit in 2019.

But for other Australians living in states and territories without VAD laws, the choices currently offered them can be grim.

It is legal, if you are dying and suffering beyond medical help, to end your suffering by committing suicide. Most often this happens violently and alone. According to statistics from the state coroners, around one in ten suicides in any year are carried out by people with terminal or debilitating chronic illness. Each month in Queensland, for example, around seven terminally ill people take their own lives.³

It is legal to refuse all medical treatment, food and water, in the hope that, aided by starvation and dehydration, your disease will more quickly take its course. Your choice to do this will be medically supported. It can take days or weeks, and is not defined in law as suicide.

It is legal for a doctor to slowly drug you into a coma while your family waits for days, or weeks, for you to die. This can happen without your consent.

In other words, the law already recognises that a dying person has a right to hasten their own death in order to bring an end to their suffering. Only, existing law means that such choices can be cruel, causing great trauma for the person dying, their families, and their carers.

It is *not* legal in most states, if you are dying and suffering beyond medical help, to end your suffering painlessly and quickly with the help of a doctor, at

a time of your choosing, and with an opportunity to farewell those you love.

As a patient, you have no legal right to insist that a doctor gives you more, or faster, pain relief. That decision is entirely up to the doctor whose personal beliefs you may not share.

Except in Victoria, and from mid 2021 in Western Australia, the law does not protect doctors who act compassionately to relieve intractable suffering by accelerating death. The law encourages individuals to keep their plans to end their life secret from family to avoid them becoming an accessory. The law compels terminally or hopelessly ill people intent on taking their own lives to do so before they lose their physical or mental capacity.

THREE AUSTRALIAN PARLIAMENTARY SELECT COMMITTEES, WORKING INDEPENDENTLY, HAVE RECOMMENDED VAD BE MADE LEGAL.

The length of life lost in such cases is a tragedy for the individual and all who loved them. This is why every parliamentary committee looking at the issue has recommended, by a majority, that VAD be made law:

- 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.

A historic level of consultation

Over the last five years, the landscape in Australia around the debate on voluntary assisted dying has changed dramatically.

In this time, we have witnessed three of the most comprehensive examinations of end-of-life care ever undertaken. Though conducted independently, these cross-party parliamentary inquiries, in Victoria, Western Australia and Queensland, found Australia's existing end-of-life laws to be inadequate.

All recommended, by a clear majority, that VAD be legalised as part of a broader approach to better end-of-life care, including more resources for palliative care.

The most recent of these select committee inquiries, in Queensland in 2019/20, received more than 5,000 submissions and heard from hundreds of people via public consultations. People of all ages and from all walks-of-life described with great clarity the damage being done in the absence of VAD laws.

In Western Australia, the successful Voluntary Assisted Dying Act (2019) was the result of a similar inquiry process – one of the biggest public and community consultations ever undertaken in WA. Running for more than 12 months, the 2018 Joint Select Committee Inquiry into End of Life Choices received more than 700 submissions and held 81 public hearings.

The Queensland and Western Australian processes, in turn, were built on the foundations of Victoria's ground breaking inquiry, held over 10 months in 2016. This parliamentary inquiry committee considered 1074 submissions and heard from 154 witnesses. Members travelled to jurisdictions around the world where forms of voluntary assisted dying already existed to collect evidence.

- **3 PARLIAMENTARY INQUIRIES**
- **200+ PUBLIC HEARINGS**
- **A RAFT OF INTERNATIONAL, PEER-REVIEWED EVIDENCE**

The successful bills in WA and Victoria were further aided by the work of Ministerial Expert Panels. These panels, consisting of palliative care and other medical experts, former state and federal presidents of the AMA, and expert advisors from the legal, disability and Indigenous communities, heard from hundreds of participants through public forums, roundtables and other meetings and received thousands of written submissions

Supporting these forensic investigations and consultations is a raft of international, peer-reviewed evidence gathered from multiple jurisdictions with VAD laws in place. Jurisdictions where, after 10, 15 and even 20 years, there is still widespread public and political support for assisted dying; where fears about the abuse of the vulnerable have not been realised; and where there is no loss of faith in doctors or degradation in palliative care – in fact their opposite.

Few, if any, laws tabled in Australian parliaments have been underpinned by such extensive consultation and expert thought.

Who is this law for?

The limits of palliative care

While palliative care accommodates the needs of the majority of dying people, even the best-resourced service cannot relieve the extreme suffering some endure. This fact is acknowledged universally by responsible organisations and professionals involved in the palliative care industry. Western Australia's Parliamentary Committee found that:

*It is clear from the evidence that even with access to the best quality palliative care, not all suffering can be alleviated. Palliative care physicians themselves acknowledge this.*⁴

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 Their suffering, as recorded in evidence to the 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 world⁹, these responses reflect the reality of modern medicine, which can keep us alive longer but which still has no cure for diseases 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**

Beyond pain

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 and who visited Australia in 2019, explains from his experience¹¹ some of the conditions which are difficult to palliate and which may lead a person to request VAD (see page 13).

Dr Roger Hunt MD, a specialist in palliative medicine for three decades, who sat on the WA Ministerial Expert Panel, 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.¹²

In his book, *The Nature of Suffering and the Goals of Medicine* (2004), Dr Eric Cassell, Emeritus Professor of Public Health at the Weill Medical College of Cornell University, a member of the Institute of Medicine of the National Academy of Sciences and a Master of the American College of Physicians, describes suffering as:

An affliction of the person, not the body.¹³

Professor Cassell 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.¹⁴ (Emphasis is ours)*

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](http://thebrokenhearted.org.au) (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 pain killers 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, commonly without the explicit consent of the patient.

In order to avoid accusations of intending to hasten death, the delivery of sedatives and analgesics is slowly titrated upwards,

which means that control of pain and suffering may take some days to achieve. As nutrition is withheld, it can take up to two weeks for the patient to die.

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

**70% OF DOCTORS AGREE
PALLIATIVE CARE CANNOT
ADEQUATELY ALLEVIATE ALL
PATIENTS' SUFFERING**

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 unremitting</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 B | Questions raised by MPs

Will this law encourage elder abuse and coercion?

The elder-abuse-and-coercion argument suggests that family members or carers could pressure or 'steer' an elderly patient to request assistance to die, for instance, so that they may access an inheritance sooner.

A VAD law makes such abuse less likely, not more, by bringing practices that are currently happening in secrecy into the light.

It encourages better practice. It brings regulation and scrutiny to a space that is currently unregulated. It offers the vulnerable the protections they currently do not have.

Proposed voluntary assisted dying laws come with strict eligibility criteria and strong safeguards to ensure they apply only to those for whom the law is written. To qualify, a person has to have an extreme medical condition which, in the assessment of two doctors, independent of each other, is clearly leading to their death and which can no longer be treated in a way that will meaningfully ease their suffering.

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

There is far more involved in accessing assisted dying than a patient merely requesting it. 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 license or going to jail.

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

WA's Ministerial Expert Panel found that:

... Where voluntary assisted dying is practiced, systematic reviews have found that coercion is rare. Data from the Netherlands and Oregon show that 'members of vulnerable groups are no more likely to receive assistance in dying ... with the sole exception of people with AIDS'. The researchers concluded: 'the available data ... shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges'. 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.¹⁵

On 9 August 2019, the *Journal of the American Medical Association*, reported on Medical Aid in Dying (MAID) laws in Oregon and Washington State:

Most patients who acquired lethal prescriptions had cancer or terminal illnesses that are difficult to palliate and lead to loss of autonomy, dignity, and quality of life. Concerns that MAID would unintentionally target socially disadvantaged patients have not materialized.¹⁶

Representatives of peak elderly and disability groups in Europe and North America also report no abuse of their members under these laws.¹⁷

Proposed VAD laws in Australia are designed with multiple safeguards to protect against the risk of abuse of the vulnerable. They mandate that doctors involved in assessing patients for eligibility be specifically trained to assess possible coercion, and also capacity.

Compare this to existing end-of-life practices – terminal sedation and voluntary refusal of food and fluids – where there is little, or no, regulation or

oversight, no central record kept, and no requirement for doctors to examine either capacity or the potential for coercion.

The proposed laws also involve a level of real-time scrutiny – with serious penalties for abuse – which are unique in end-of-life care. It would be far easier to steer or coerce a patient into ending their life by overdosing on their medication, or by encouraging them to suicide (options available now), than it would be via these laws.

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

On 28 July 2018, the then AMA WA President, Dr Omar Khorshid, admitted that doctors already routinely hasten death, telling journalists: “We (doctors) shorten patients’ lives regularly if that is the right thing to do at the very end-of-life”.¹⁸

Under existing law, when Australian doctors illegally assist a person to die, we do not know if that person has been subject to abuse or coercion.

We also do not know – and do not ask – if a dying person’s decision to refuse treatment, food and water has been made under pressure, subtle or otherwise.

A VAD law brings these practices that are currently happening in secrecy into the light.

It encourages better practice. It brings regulation and scrutiny to a space that is currently unregulated. It offers Australia’s vulnerable the protections they currently do not have.

It is appropriate to raise concerns about elder abuse and the abuse and coercion of the disabled. 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 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 a vulnerable person 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 their 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. Opponents 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 (as discussed earlier).

There are also patients with chronic and progressive illnesses – such as advanced MS or motor neurone disease – who, because of the long-term nature of their suffering, do not 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 Australian wish to die at home but only 14% do.¹⁹

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.²⁰

Even so, the evidence shows that a voluntary assisted dying law will lead to *better* palliative care.

A 2018 report by Palliative Care Australia on the international situation 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.²¹

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

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

That palliative care and VAD go together is borne out in Oregon where 90% of terminally ill patients who choose a doctor's help to die are also enrolled in hospice 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.

“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.”²²

**PROFESSOR IAN MADDOCKS,
THE 'FATHER' OF AUSTRALIAN PALLIATIVE CARE,**

Won't VAD lead to doctor shopping?

The suggestion is that a patient seeking an assisted death under the proposed VAD laws could simply go 'doctor shopping' until they found one who agreed to help them.

The first and foremost eligibility requirement to access VAD is a terminal illness. The number of doctors visited cannot change this fact. Speaking practically, it would be near-impossible for a seriously ill patient to go doctor shopping. Taking the Victorian and WA laws as a guide:

First, in both the WA and Victorian laws, when deciding the eligibility of a patient for VAD, doctors must consult a second practitioner. Both doctors must report to the Review Board. The second practitioner is chosen by the first practitioner, not the patient.

So, doctor shopping, if it is to take place at all, is restricted to the patient's choice of the primary, coordinating practitioner. There are three possible scenarios where the patient could conceivably 'shop around':

- The chosen doctor declines or is ineligible to act as the coordinating practitioner (leaving the patient very little choice but to look for another doctor). Note that the Board will be aware of this, since the chosen doctor must inform the Board.
- Usually, the request and assessment process ends as a result of the assessment of the coordinating practitioner. Regardless of whether or not the patient informs their new choice of coordinating practitioner of this prior outcome, the Board will be aware of what is going on, since it will have the report of the previous coordinating practitioner.
- The second, consulting practitioner assesses the patient as ineligible. Doctor shopping by the patient at this point could not help but arouse suspicion, since the normal procedure would be for the coordinating practitioner to refer to another consulting practitioner.

Doctors may complain that all this reporting ties them up in knots, but the important point here is that it acts as a major constraint on the likelihood a patient will abuse

the system. In this respect it is quite unlike the classic 'doctor shopping' scenario, where the patient:

- is mobile and can readily move from suburb to suburb,
- relies on the fact that neither the new doctor, nor the authorities, are aware in real time of what they are doing,
- is able to present clinically with an illness that cannot be readily investigated or confirmed on the spot by the new doctor,
- expresses urgency in the need to have the required restricted drug.

Second, we are talking about people at the end stage of a serious illness. Their capacity to keep looking around for a 'correct diagnosis' – which would already be apparent from their medical records anyway – would be extremely limited. This is not a 'lifestyle choice'. And, no matter how many doctors they see, the bar never lowers. They have to meet all the eligibility criteria to qualify – eligibility criteria examined in real time and compared against the opinion of a second doctor by the VAD Review Board.

That doctor shopping doesn't happen is borne out by the most recent statistics of the number of VAD prescriptions written in North America.

In 2019, in **Oregon**, a total of 112 different physicians wrote prescriptions for 290 individuals.²³

In 2018, in **Washington**, a total of 158 different physicians wrote prescriptions for 267 individuals.²⁴ The medication was dispensed by 61 different pharmacies.

In 2018, in **California** (latest available statistics)²⁵, a total of 180 different physicians wrote prescriptions for 452 individuals.

The AMA paints a picture of 'euthanasia enthusiast doctors' being encouraged under these laws. Based on the figures above, any such doctor (if they exist) would struggle to make a living out of the handful of patients they would see each year.

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 in 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 them to be less trustworthy.

A doctor's mission statement doesn't change under this law. They are asked to act as they ordinarily do – diagnose, prescribe and care for their patients. Remember, too, figures from Oregon show that around one in three patients prescribed VAD medication choose not to use it. Having been offered the option they elect not to take it. Ultimately, it is the person who acts, not the doctor.

Why not show VAD as the cause of death?

When somebody dying of cancer chooses to hasten their 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.

The same principle applies with assisted dying.

In their submission to the WA Ministerial Expert Panel, National Disability Services 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.²⁶

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 Commission.

What if there is a 'wrongful death'?

By definition, the only people who can access this law are at the end stages of a serious illness from which they are clearly already dying.

In the WA parliamentary inquiry process, Nick Goiran MLC made much of so-called wrongful deaths in his dissenting [Minority Report](#) arguing against a VAD law. In it he insisted that there was 'peer-reviewed evidence of abuse'. However, these claims have been reviewed and found wanting.

Analysis shows the bulk of the evidence used in this report was not peer reviewed but instead came from abbreviated versions of official reports taken out of context, newspaper stories and anecdotes told by anti-euthanasia physicians.

A detailed investigation of 26 allegations of 'wrongful deaths' presented in the Minority Report shows that only six out of 26 cases (less than a quarter) related to patients who may qualify for an assisted death (under the legislation that was being debated in Western Australia).

Twenty cases in the Minority Report were entirely irrelevant because the subjects fell outside the proposed criteria.

Of the six cases which may have been relevant to the Australian legislation:

- One concerned a woman who was only 'terminally ill' because she was reluctant to undergo chemotherapy. When her doctor did what any ethical physician would do – engage her in a discussion about her options – she relented and accepted treatment. She is still alive;
- Three recount incidents that occurred in the Northern Territory over 21 years ago under highly idiosyncratic circumstances;
- One concerned a patient being injected while in a coma – an irrelevant concern for a law which requires patients with capacity to self-administer a lethal drink or consent to doctor administration, under strictly prescribed circumstances;
- One has been rejected as 'lacking veracity' by the CEO of the health care provider in which the incident occurred; and
- In four of the 'wrongful deaths' presented in the Minority Report, the subjects are, as far as can be ascertained, still alive;
- In two cases, the subjects were not approved for assisted deaths and died by their own hands.

See a comprehensive analysis of the claims in [The Full Picture: A Critical Analysis of Allegations of 'Wrongful Deaths' in Hon. Nick Goiran MLC's Minority Report](#).

The threat of 'wrongful deaths' is also not supported by multiple systemic, peer-reviewed studies from overseas, studies accepted by several Australian parliamentary committees.

In making it the argument, the author claims that a regulated system with a level of real-time scrutiny of doctors is less safe than the current unregulated system where doctors admit to illegally assisting people to die.

Is feeling like a burden the reason to choose a voluntary assisted death?

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 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 context²⁷, 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 MND – can all be seen on the yearly reports published by the Oregon Department of Health.²⁸

Since its inception in 1997, nobody – not a single person – in Oregon accessed voluntary assisted dying 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 same criteria will apply elsewhere.

CHARACTERISTICS	2019		TOTAL	
	(N=188)		(N=1,657)	
END OF LIFE CONCERNS				
Less able to engage in activities making life enjoyable (%)	170	(90.4)	1,480	(89.3)
Losing autonomy (%)	163	(86.7)	1,494	(90.2)
Loss of dignity (%)	136	(72.3)	1,131	(74.0)
Burden on family, friends/caregivers (%)	111	(59.0)	773	(46.7)
Losing control of bodily functions (%)	74	(39.4)	728	(43.9)
Inadequate pain control, or concern about it (%)	62	(33.0)	440	(26.6)
Financial implications of treatment (%)	14	(7.4)	71	(4.3)

SOURCE: OREGON DEATH WITH DIGNITY ACT, 2019 DATA SUMMARY²⁹

Why a different consideration for people with a neurological disease?

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

Legislation in North America requires that a person who has a terminal disease be able to access voluntary assisted dying. The most common terminal diagnosis for accessing voluntary assisted dying in these jurisdictions is cancer. The European jurisdictions of the Netherlands and Belgium do not require a person to have a terminal disease to access VAD.

In WA, a time frame to death was put on the law because, in the Ministerial Expert Panel's view:

Assisted dying is intended to provide an option that can limit suffering at the end-of-life, not a way to end life for those who are not dying.

While a time frame to death is a feature of the Victorian and Western Australian laws, there is no necessity to stipulate a time frame if the legislation makes it clear the law is only for people at the end of their life. The spelled-out time periods were deemed appropriate in VIC and WA, but each legislature will draft a bill according to what most appropriate for their situation.

A time frame to expected death is referenced extensively in palliative care in Australia, 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?"). It is consistent with existing end-of-life and palliative care policy documents such as the National Consensus Statement: Essential Elements for Safe High-Quality End of Life Care and various state strategies.³⁰

However, there may be good arguments not to include a time frame, especially for people with degenerative chronic or neurological conditions. Often the progression of these diseases are 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.

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

People with terminal and debilitating chronic illnesses make up around 10% of suicides each year in Australia, as

indicated by evidence to the Victorian, WA and Queensland inquiries. These violent and lonely deaths will continue in our community as long as there is no law to offer these people a peaceful choice.

Ironically, in allowing these people a humane way in which to control their circumstances, many of them will choose to live longer knowing that 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 when they see no other option but to take matters into their own hands.

Lawrie died alone in January 2018, without the opportunity to say goodbye to his loved ones face to face. 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."

Watch Lawrie's Last Letter here:

https://www.gogentleaustralia.org.au/lawrie_daniel

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

Why a waiting period between first and last request?

Some argue against a minimum waiting period on the basis that, whatever time period is landed on, it is never long enough.

The legislation recognises the need to guard against impulsive decisions by people experiencing extreme physical and emotional pain to ensure they are not accessing voluntary assisted dying without proper consideration.

Medical practitioners routinely assess whether medical treatment decisions are properly considered by their patients. Under these laws, two doctors, with training in assessing both capacity and the prospect of coercion, will do just that.

The primary (coordinating) medical practitioner is best placed to judge the enduring nature of a person's request in the context of the trajectory of their condition. The independent secondary (consulting) medical practitioner is best placed to act as a safeguard to ensure the judgement of the coordinating doctor is reasonable. The legislation allows that these assessments, combined with the requirement that a patient be 'at the end-of-life', provide the necessary protection to ensure requests are properly considered, while also taking into account a person's condition and likely deterioration.

The time between each step in the process would, of itself, provide some period for reflection. The person would always have the protection of being able to withdraw from the process at any stage.

That a person's decision is enduring would be shown through several of the proposed process steps: the initial request, participation in the first assessment, the written declaration, participation in the second assessment, the request that triggers the provision of the prescription and the request for administration of the medication (if not self-administered).

In most jurisdictions there is some form of prescribed waiting period of anywhere between nine and 17 days.

For example, under the Dying With Dignity Act passed in Oregon in 1997 a person seeking assistance to die was required to make a verbal request, wait 15 days and then make a written request. They then had to wait an additional 48 hours before obtaining the prescription.

Subsequent research showed, however, that one in five people who made their initial request in Oregon died before they are able to complete the process.³¹

In 2019, in an acknowledgment that the intention of the law was not to force eligible patients to suffer unnecessarily while they waited, Oregon lawmakers acted.

They amended the legislation (the only change in 25 years) so that doctors could make exceptions to the waiting periods **if the patient was likely to die before completing them**. A similar provision has been built into the Victorian and Western Australian laws.

That this is a compassionate and sensible provision was shown in a number of submissions to the WA Ministerial Expert Panel:³²

... 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 that the person will die before the waiting period has elapsed (as in Victoria).
– Submission by Bethesda Health Care.

What's the difference between VAD and suicide?

The distinction between suicide and a rational decision to end 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 chose to jump. Seeing this as a rational choice to avoid needless suffering, Hirsch refused to classify their deaths as 'suicides'.³³

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.*³⁴

The Lifeline position on the linking of assisted dying and suicide is:

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*³⁵

The reality is that the absence of VAD laws contributes to suicides. Key findings of the WA Parliamentary Committee were:³⁶

[Finding 33] The prohibition of a peaceful, assisted death has driven some terminally or chronically ill individuals to suicide using violent means.

[Finding 34] Some individuals who suicide under these circumstances are driven to take their lives early.

All deaths under these circumstances are tragic and very often traumatic and distressing to family, friends and first-responders.

[Finding 35] 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.

Of the many compelling pieces of evidence to come from that inquiry was this from the State's Coroner: That one in ten suicides in WA in any year are by people suffering with terminal or debilitating chronic diseases. Evidence in the Coroner's report included the following:³⁷

- 199 cases where people who had been diagnosed with a terminal illness committed suicide.
- There were one hundred (100) cases identified where the deceased was diagnosed with a terminal or debilitating condition and experienced a decline proximate to their death.

1 IN 10 SUICIDES IN WA, FOR EXAMPLE, ARE BY PEOPLE WITH TERMINAL OR DEBILITATING ILLNESSES

- From 2012 to 2017, there was an average of forty-one (41.0) deaths of relevance reported per calendar year.

The Victorian and Queensland Parliamentary committees made similar findings: In Victoria, prior to the introduction of that state's VAD law, the coroner estimated around 10% of suicides were by people with chronic, debilitating or terminal illnesses. In Queensland, figures from the National Coronial Information Service showed seven people with terminal or debilitating conditions kill themselves every month, amounting to 168 deaths in 2016 and 2017.

Is the VAD medication reliable?

The success rate of assisted dying medication in North America is extraordinarily high.

Oregon

In Oregon, of 1,657 deaths between 1998 and 2019:

- 30 people had difficulty ingesting (or regurgitated) the medication (1.8%)
- 2 people had seizures after taking the medication (0.1%)
- 8 people (0.5%) had regained consciousness after ingesting DWDA medications
- 15 people had other unspecified complications (0.9%).³⁸

Of 1,657 deaths, 55 people (3.3%) had some complication (not necessarily serious and not necessarily due to a fault with the drug) during or after ingesting the medication. This equates to 2.5 incidents per year over 22 years.

Washington

Between 2016 and 2018, of 540 deaths, complications were reported in 21 patients (4%). This equates to about seven patients per year over three years (the period covered in the 2018 report). In 2018, of 195 deaths, there were eight reported complications (4%).³⁹

The regurgitations mentioned are not failures, they are simply cases where the patient had a slight negative reaction to the bitter taste of the medication or had been nauseous prior to taking the medication or had some form of blockage. But, nonetheless, they died peacefully.

In the few cases in Oregon where patients awakened, they may have ingested only a portion of the medication before they fell asleep, or they may have mixed the medications too far in advance and let it sit on a shelf, which caused a decrease in potency or crystallisation. In one case, more than 15 years ago, an inadequate dose for the patient's weight was prescribed.

No medical procedure is perfect. A success rate well in excess of 95% is extraordinarily high.

The WA Ministerial Expert Panel also found that:

Despite the concerns raised in the consultation, the Panel noted there is no evidence of misuse with voluntary assisted dying medications elsewhere in the world.⁴⁰

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

Suffering is an intensely personal experience and is not confined to physical experience or pain.

Many symptoms experienced by people suffering life-limiting illnesses are more difficult for the medical profession to assess and treat. Even with the best palliative care, both dying and incurably ill people face a range of symptoms that are difficult to manage. 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 also leads to obstruction of swallowing, obstruction of the intestine, with vomiting and, ultimately, starvation
- paralysing diseases of nerves supplying the muscles of the chest and throat that cause gasping or choking to death (such as with MND)
- mesothelioma (an asbestosis-related disease that is incurable), which produces severe chest pain with each breath, causing difficulty in breathing and feelings of suffocation
- difficult to treat neuralgia that causes experiences similar to electric shock, 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.

If you've had an accident, and a doctor wants to find out how much something is hurting, they're not going to tell you – they're going to *ask* you. Only the patient can

determine the level of their own pain and whether or not it is tolerable. However:

- Under the laws in WA and Victoria, two doctors also have to agree that what you say is intolerable suffering matches their reasonable expectation, based on your medical history and symptoms, of what intolerable would be.
- It's important to remember that, because you must have a terminal (and, by definition, terrible) 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, knows the trajectory of your disease, 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 for that disease, is going to consult your medical records. They will want proof – because all the records of a lawfully approved VAD request will go to the Review Board for examination – that you have the disease you say you have and that it has reached the point of intolerable suffering.
- Even then, should they be convinced – both doctors, independently – that your suffering is intolerable, they still have to canvas all treatment options with you.
- This is not a one-off consultation. Like all complex medical treatments, it is an ongoing conversation with your doctor.

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 daughters⁴¹. A version can also be read in *The Age*.⁴²

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 state-wide 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 women 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 state-wide pharmacy to meet with Kerry.
- **15 July** – medication is dispensed; Kerry takes it the same day.

Part C | Questions for legislators

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

There is a clear body of evidence that demonstrates that assisted dying already occurs despite being unlawful. This includes research that examines doctors' intentions when administering pain-relieving medication and whether the provision of this treatment always complies with the law.

As discussed elsewhere in this booklet, 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 kill is not lawful.

Despite this, some doctors who are treating terminally ill patients intend to kill 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'.

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.

Does this law protect religious freedom?

Medical professionals can refuse to participate in VAD due to moral or ethical convictions without sanction or criticism.

Many doctors also have strong religious beliefs that guide their approach to medical care. Australia's Catholic palliative care services are guided by the Vatican's Instructions for Health Care Workers:

Pain in the final moments of life can take on spiritual significance for the sick person and... can be accepted as... 'union with the redemptive sacrifice of Christ'... it is therefore necessary to give an evangelical meaning to death.⁴³

A voluntary assisted dying law respects the right of any doctor or nurse to conscientiously object. In so doing, it respects religious freedom.

At the same time it protects a patient's right not to have those beliefs imposed upon them.

It is the core principle embodied in the first word of voluntary assisted dying – 'voluntary'.

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

There are aspects of the current law in relation to end-of-life care that 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 to commit 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 not.⁴⁴

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.*⁴⁵

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 can 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.*⁴⁶

That doctors hold strong personal beliefs that 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. Any proposed VAD law, rightly, protects and respects a doctor's right to act according to their 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 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%.⁴⁷ 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)⁴⁸, The Roy Morgan Snap Poll (2017), *The West Australian* (2018 and 2019),⁴⁹ and ABC's Vote Compass (2019).

This support also extends into the medical professions. A significant number of doctors, nurses and allied health professionals support patient choice at the end of life.

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, and the Australian Nursing and Midwifery Federation, have all either backed a VAD law or adopted a neutral stance.

According to a 2016 survey conducted by the Australian Medical Association (AMA), a majority of members (51.6%) agreed assisted dying "can have a legitimate role in modern medical care".

Yet the AMA, which represents not even 30% of doctors (and less than 25% in some states) continues to oppose assisted dying, ignoring the views of a significant proportion of its membership.

In WA, two former state AMA presidents served on the Ministerial Expert Panel that provided recommendations on the VAD bill to the government.

Both have publicly distanced themselves from the official AMA stance, with one former president, Dr Scott Blackwell, declaring that he is disappointed with the AMA's "alarmist and concerning" commentary.

*[The commentary 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.*⁵⁰

**51.6% OF AMA MEMBERS
AGREE THAT 'EUTHANASIA
CAN FORM A LEGITIMATE
PART OF CARE'⁵¹**

Part D | 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:

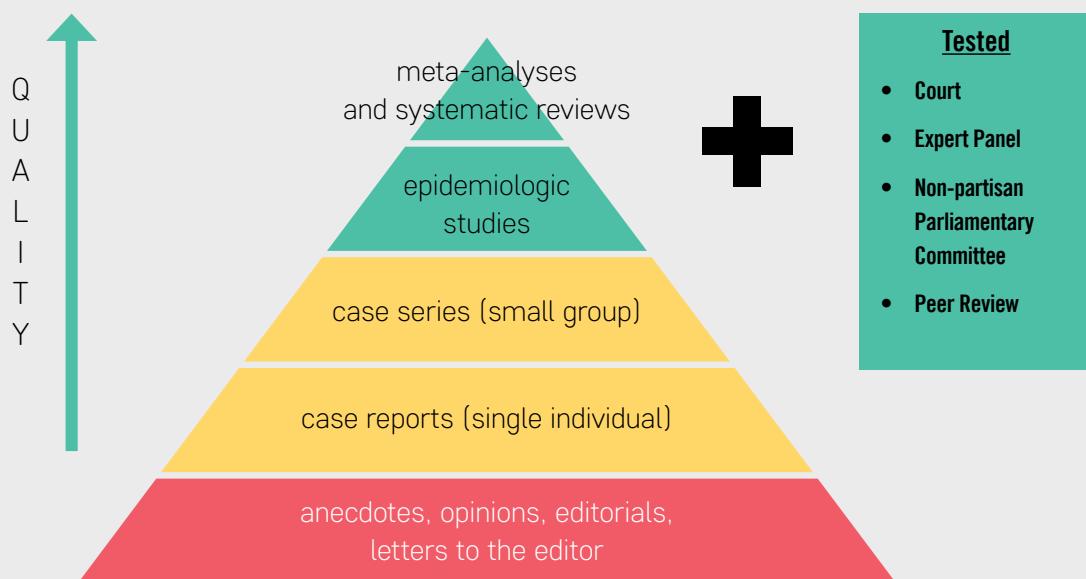
Voluntary assisted dying is a critical social issue. Both sides of the argument have a duty and responsibility to be transparent in their views and also to be clear about the evidence they are relying on. Where there is trustworthy, reliable evidence that sheds light on how voluntary assisted dying regimes 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.

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.⁵²

So, if you are looking for information and want to know if it is credible or not, a starting point would be to look at who is the author. 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 FOUNDATION ⁵³

A report⁵⁴ prepared in 2018 by the conservative Institute of Public Affairs (IPA) think-tank and the progressive Per Capita think-tank, investigated 20 policy decisions in recent years by the federal Coalition government, the NSW Liberal government, and Queensland and Victorian Labor governments.

Despite differing outlooks, the IPA and Per Capita agreed on what were good and bad policy processes. At the very top of their list of good policy was Victoria's voluntary assisted dying legislation. If this exercise were repeated today, Western Australia's VAD law would similarly appear at the top of the list.

The director of policy at the IPA, Simon Brehny, said that in a period of "declining trust in politicians,

democracy and institutions, it is essential now more ever that policy making is undertaken in a thorough and consultative manner".⁵⁵

Good policy process – from actually undertaking cost-benefit analysis to having a detailed plan for how a policy will be rolled out – is not a left-right issue; it is an issue of competency.

According to Emma Dawson, the executive director of Per Capita Australia,

Our assessment of the selected policies against the agreed criteria revealed the importance of taking a rigorous and consultative approach to policy development and implementation at all levels of government.

Political Hits and Misses

Average rating from the think tanks on key issues

EXCELLENT



VICTORIA:	VOLUNTARY ASSISTED DYING LAW 2017	9/10
QLD:	LEGALISING RIDE-SHARING APPS	9/10

SOUND



NSW:	CRIMINAL JUSTICE REFORMS	8.5/10
VICTORIA:	ACCESS TO MEDICAL CANNABIS 2016	8/10

ACCEPTABLE



FEDERAL:	ELECTORAL AMENDMENT ACT 2016	7.5/10
NSW:	GREYHOUND RACING LAWS 2016, 2017	7/10

UNACCEPTABLE



FEDERAL:	CREATION OF HOME AFFAIRS DEPARTMENT	2/10
FEDERAL:	SAME-SEX MARRIAGE POSTAL SURVEY	2.5/10
NSW:	LOCAL COUNCIL MERGERS	2.5/10
QLD:	VEGETATION MANAGEMENT LAWS 2018	2.5/10

SOURCE: NEWDEMOCRACY FOUNDATION ⁵⁶

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; (see page 29)
- 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 cruel their death needs to be;
- **Finally, never forget that this law is a clock.**

Endnotes

1. Gish Gallop - Wikipedia https://en.wikipedia.org/wiki/Gish_gallop
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>
3. Felicity Calwell, 'Every month, seven terminally ill people take their lives in Queensland' The Brisbane Times, 1 Sept 2019 <https://www.brisbanetimes.com.au/politics/queensland/every-month-seven-terminally-ill-people-take-their-lives-in-queensland-20190830-p52me5.html>
4. A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018, – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>
5. Palliative Care Australia, "Policy statement on voluntary euthanasia", Canberra, 2006, p.2. Quoted by: Neil Francis, "AMA uncovered: How its own review exposed its assisted dying policy as indefensible", Dying for Choice, 27 March, 2017, p.20 – <http://www.dyingforchoice.com/docs/AMAUncoveredFullReport27Mar2017.pdf>
6. Claire Moodie, "With his death he made a statement": Clive Deverall's widow speaks out on euthanasia", news report and video, ABC News 20 September, 2017 (see quoted content in video at 4:00) – <https://www.abc.net.au/news/2017-09-19/clive-deveralls-widow-speaks-out-on-euthanasia/8882854>
7. Roger Hunt, "Re P.C. Figures", Email to Andrew Denton, Go Gentle Australia, 23 July, 2017.
8. Australian Medical Association, "Review of AMA Policy on Euthanasia and Physician Assisted Suicide - Member Consultation Report", 2016.
9. The Economist, "The 2015 Quality of Death Index: Ranking Palliative Care Across the World". A report by the Economist Intelligence Unit, 2015. <https://eiuPerspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>
10. Noreen Fynn, "Submission to the Joint Select Committee on End of Life Choices (Western Australia)", 17 October, 2017 – [http://www.parliament.wa.gov.au/parliament/commit.nsf/\(Evidence+Lookup+by+Com+ID\)/30D73154F4D00AFF48258219000B3C84/\\$file/20171017+++EOLC+++Sub+347+++Ms+Noreen+Fynn.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/30D73154F4D00AFF48258219000B3C84/$file/20171017+++EOLC+++Sub+347+++Ms+Noreen+Fynn.pdf) Noreen Fynn is the widow of Clive Deverall
11. Dr David Grube MD, visit to Western Australia, August 2019, facilitated by Go Gentle Australia.
12. Roger Hunt, 'Submission 779: Inquiry into End of Life Choices', 11 August 2015, viewed 19 July 2017, https://www.parliament.vic.gov.au/images/stories/committees/Isic/Submissions/Submission_779_-_Roger_Hunt.pdf.
13. Cassell, Eric, The Nature of Suffering and the Goals of Medicine, Oxford University Press, 2004, p.xii. Google Books edition, viewed 19 July 2017, <https://books.google.com.au/books/about/The_Nature_of_Suffering_and_the_Goals_of.html?id=BiqTtq5uZwC&redir_esc=y>
14. Ibid. p. 289
15. Malcolm McCusker QC Ministerial Expert Panel on Voluntary Assisted Dying, Final Report 2019, page 27 "Decision Making Capacity". <https://www2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Voluntary%20assisted%20dying/PDF/voluntary-assisted-dying-final-report.pdf>

16. Al Rabadi L, LeBlanc M, Bucy T, et al. Trends in Medical Aid in Dying in Oregon and Washington. JAMA Network Open. Published online August 09, 2019;2(8) <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2747692>
17. Andrew Denton, "Better Off Dead: #13 Now they're killing babies", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 24 March 2016, (audio) <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/13-now-they-re-killing-babies> Transcripts available at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2>
18. Seven News Saturday, July 28, 2018 <https://www.redfm.com.au/news/news/dr-alida-lancee-why-i-stood-up-for-compassion-and-choice-and-back-assisted-dying-laws-ng-b88917737z/>
19. Hal Swerisson and Stephen Duckett, Dying Well The Grattan Institute, September 2014 <https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>
20. The Economist "The 2015 Quality of Death Index: Ranking Palliative Care Across the World". A report by The Economist Intelligence Unit, 2015. <https://eiu.perspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>
21. Aspx Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018,
22. Ian Maddocks, Correspondence with Go Gentle Australia, 2017
23. Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: 2019 Data Summary", Oregon Public Health Authority, February 25, 2020, p.12 – <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year22.pdf>
24. Death with Dignity Act Report - 2018 - <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2018.pdf>
25. California End of Life Option Act Report - 2018 (latest available) - <https://www.deathwithdignity.org/wp-content/uploads/2019/08/CA-CDPH-End-of-Life-Option-Act-Report-2018.pdf>
26. Malcolm McCusker QC Ministerial Expert Panel on Voluntary Assisted Dying, Final Report 2019, page 70 "Reflecting on the Decision". <https://www2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Voluntary%20assisted%20dying/PDF/voluntary-assisted-dying-final-report.pdf>
27. Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2018", Oregon Public Health Authority, February, 25 2019, p.12 – <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>
28. Death with Dignity, "Annual Oregon Death with Dignity Reports" <https://www.deathwithdignity.org/oregon-death-with-dignity-act-annual-reports/>
29. Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: 2019 Data Summary", Oregon Public Health Authority, February 25, 2020, p.12 – <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year22.pdf>
30. WA End-of-Life and Palliative Care Strategy 2018-2028 <https://www2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf>
31. Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, "Physicians' Experiences with the Oregon Death with Dignity Act", New England Journal of Medicine, 342, 24 February, 2000, pp. 557-563 – <http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>
32. Malcolm McCusker QC Ministerial Expert Panel on Voluntary Assisted Dying, Final Report 2019, page 177 "Distinguishing Between Suicide and Assisted Dying", <https://www2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Voluntary%20assisted%20dying/PDF/voluntary-assisted-dying-final-report.pdf>
33. Vickers, Matt, Lucretia's Choice: A Story of Love, Death and the Law, Text Publishing, 29 August, 2016, p. 231 – <http://tinyurl.com/y36mt867>
34. A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices", page xxxviii 40th Parliament, Parliament of Western Australia, August, 2018 [http://www.parliament.wa.gov.au/Parliament/commit.nsf\(Report+Lookup+by+Com+ID\)/71C9AFECD0FAEE6E482582F200037B37/\\$file/Joint%20Select%20Committe%20on%20the%20End%20of%20Life%20Choices%20-%20Report%20for%20Website.pdf](http://www.parliament.wa.gov.au/Parliament/commit.nsf(Report+Lookup+by+Com+ID)/71C9AFECD0FAEE6E482582F200037B37/$file/Joint%20Select%20Committe%20on%20the%20End%20of%20Life%20Choices%20-%20Report%20for%20Website.pdf)
35. "Lifeline Position Statement on Euthanasia, 2013". Email to Go Gentle Australia, Lifeline WA, 10 July 2019
36. A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices", page xxxviii 40th Parliament, Parliament of Western Australia, August, 2018 [http://www.parliament.wa.gov.au/Parliament/commit.nsf\(Report+Lookup+by+Com+ID\)/71C9AFECD0FAEE6E482582F200037B37/\\$file/Joint%20Select%20Committe%20on%20the%20End%20of%20Life%20Choices%20-%20Report%20for%20Website.pdf](http://www.parliament.wa.gov.au/Parliament/commit.nsf(Report+Lookup+by+Com+ID)/71C9AFECD0FAEE6E482582F200037B37/$file/Joint%20Select%20Committe%20on%20the%20End%20of%20Life%20Choices%20-%20Report%20for%20Website.pdf)
37. Ibid.

38. Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: 2019 Data Summary", Oregon Public Health Authority, February 25, 2020, p.12 – <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year22.pdf>
39. Death with Dignity Act Report - 2018 - <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2018.pdf>
40. Ministerial Expert Panel on Voluntary Assisted Dying (Western Australia), June 2019, Final Report, 'Safe Return of Unused Medication' Discussion, page 87 <https://www2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Voluntary-assisted-dying/PDF/voluntary-assisted-dying-final-report.pdf>
41. Interview with Nicole Robertson and Jacqui Hicks, Go Gentle Australia, 29 July 2019
42. Melissa Cunningham "She left with courage and grace": Daughters farewell Victoria's first person to access assisted dying' The Age Aug 4 2019 <https://www.theage.com.au/national/victoria/she-left-with-courage-and-grace-daughters-farewell-victoria-s-first-person-to-access-assisted-dying-20190802-p52d97.html>
43. The Pontifical Council for Pastoral Assistance to Health Care Workers, "Charter for Health Care Workers" <https://www.ncbcenter.org/resources/church-documents-bioethics/new-charter-health-care-workers/> Accessed 11 March 2019.
44. Bob Douglas, Lindy Willmott and Ben White "The right to choose an assisted death: Time for legislation". Australia 21 /QUT Report http://australia21.org.au/wp-content/uploads/2013/08/J2056-Assisted-Death-Report_WEB.pdf
45. Ronald Dworkin et al The Philosophers' Brief 1997 to the US Supreme Court, quoted in A Good Death: An Argument for Voluntary Euthanasia by Rodney Syme, 2008, Melbourne University Press
46. Noreen Fynn, "Submission to the Joint Select Committee on End of Life Choices (Western Australia)", 17 October, 2017 [http://www.parliament.wa.gov.au/parliament/commit.nsf/\(Evidence+Lookup+by+Com+ID\)/30D73154F4D00AFF48258219000B3C84/\\$file/20171017+-+EOLC+-+Sub+347+-+Ms+Noreen+Fynn.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/30D73154F4D00AFF48258219000B3C84/$file/20171017+-+EOLC+-+Sub+347+-+Ms+Noreen+Fynn.pdf) Noreen Fynn is the widow of Clive Deverall
47. C Hanrahan, "Euthanasia support strengthens to nearly 90pc, Vote Compass date shows" ABC Online 9 May, 2019 – <https://www.abc.net.au/news/2019-05-08/vote-compass-social-issues-euthanasia-transgender-republic-drugs/11087008>
48. N Egan, "Wide Support for Euthanasia", Australian Ageing Agenda, 6 December, 2012 <https://www.australianageingagenda.com.au/2012/12/06/wide-support-for-euthanasia-poll/>
49. Gary Adshead and Peter de Kruijff "Poll Reveals Huge Support for Euthanasia Laws", The West Australian, 17 November, 2018 <https://thwest.com.au/news/wa/assisted-dying-debate-poll-reveals-huge-support-for-voluntary-euthanasia-laws-ng-b881020998z>
- Angela Pownall and Nick Butterly, 'Voluntary assisted dying: Nine out of 10 West Australians want euthanasia laws, according to poll' The Australian, 26 August, 2019 – https://thwest.com.au/news/health/voluntary-assisted-dying-nine-out-of-10-west-australians-want-euthanasia-laws-according-to-poll-ng-b881302205z?fbclid=IwAR02XcKQ3KKCaxRRd7cBqQu7P40mhaww9I2R4hH_XseUPrTI94Prs1--40
50. Australian Associated Press, 'WA assisted dying law set for long debate' 7 August 2019 https://au.news.yahoo.com/wa-assisted-dying-law-set-long-debate-064614199--spt.html?guccounter=1&guce_referrer=aHR0cHM6Ly93d3cuZ29vZ2xLmNvbS8&guce_referrer_sig=AQAAAN2Na6zxd0TjK-7-PCmVnu3Xt0FZlQ3Ep2iYux96TudK_11zkWeOhx3ZkCo8Q47mKfOeffT0edlQZ2597kZBZddp6VjdjlrJslqrHtzJY1j23uffHq9WqDPBNprHOa_CBUGPzPmj17mtgGUXyNORB0fZYyHPK5xhT9JuYFik
51. Robyn Maggs, "Pain, Choice and the Art of Dying with Dignity", The Mercury, 1 March, 2018 – <https://www.themercury.com.au/news/opinion/pain-choice-and-the-art-of-dying-with-dignity/news-story/0304ece1d4e4e4d9c792c61ab0c5947e?fbclid=IwAR2WH1VXfwJX4774mF1J-BgE5bEQ7UaISJWMW3iVYy9Obo58QJNc4EN-DqM>
52. Ben White, Interview with Go Gentle Australia for the documentary film Fatal Fraud, July 2019
53. Ben White, Andrew McGee and Lindy Willmott, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", The Conversation, 20 September, 2017 – <https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195>
54. Lesh, Matthew, "Evidenced Based Policy Research Project: 20 Case Studies", Institute of Public Affairs, October, 2018, p. 6 – <https://ipa.org.au/wp-content/uploads/2018/10/IPA-Report-Evidence-Based-Policy-20-case-studies.pdf>
55. Jessica Irvine, 'Half-baked': opposing think tanks unite to condemn policy failures' Sydney Morning Herald 5 October 2018 – <https://www.smh.com.au/politics/federal/half-baked-opposing-think-tanks-unite-to-condemn-policy-failures-20181005-p507y9.html>
56. Ben White, Andrew McGee and Lindy Willmott, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", The Conversation, 20 September, 2017 – <https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195>



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Go Gentle Australia Limited is a registered charity.

Go Gentle Australia is a health promotion charity founded by Andrew Denton. It was established to help relieve the distress, helplessness and suffering experienced by Australians with terminal illnesses, their families and carers. We are about a better conversation around death, dying and end-of-life choices, including voluntary assisted dying.

SUMMARY

1. INTRODUCTION

- Our aim is to support MPs to make well-informed, principled and evidence-based decisions on the next Tasmanian VAD Bill. Voluntary assisted dying laws are now long established, thoroughly scrutinised laws. The number of laws is increasing because of overwhelming evidence they are needed, are working safely and are highly valued wherever they have been passed.
- This paper provides a relatively brief overview of the current situation involving voluntary assisted dying legislation in Australia and overseas and some key issues. It includes links to reliable, trusted sources of relevant information which are independent of DwDTas. All views and claims for and against VAD legislation need to be checked against independent sources of accurate, relevant, reliable information.

2. INCREASING ACCEPTANCE OF THE EVIDENCE - 20 JURISDICTIONS AND COUNTING

- This section includes details of the **20 jurisdictions with a form of legal voluntary assisted dying; 16 of them with specific legislation**. New Zealand is likely to soon become the 21st.
- The section includes links to the Victorian and WA Voluntary Assisted Dying Acts.

3. VAD LEGISLATION MEETS DEMONSTRATED NEEDS, WISHES AND SUPPORT ACROSS THE COMMUNITY

- Legislation for doctor-provided voluntary assisted dying is a very rare political issue where **support is higher than for any other comparable issue, and the support is very high across the community - across religious and political affiliation, age groups and gender** in Tasmania, elsewhere in Australia and in other comparable countries.
- This section includes links to data on the high level of support for VAD generally, including among Christians, and the likely significant support of doctors for a VAD option. It includes links to policies and views of medical associations (RACGP, RACP and Canadian Medical Association) and to AMA information including a survey report, showing it is likely a majority of its members support a VAD option.

4. VAD LEGISLATION PROVIDES AN ESTABLISHED, SCRUTINISED, SAFE AND RESPONSIBLE OPTION

- **Multiple recent thorough reviews, including parliamentary inquiries**, have gathered a massive amount of evidence and the views of the community and experts. After carefully examining the evidence and views, the reviews and inquiries have reached **consistent conclusions about the need for, and the safety and value of, a legal VAD option**, as well as action on other end of life issues.
- This section includes more details and links to reviews, such as the Victorian, WA and Canadian reviews.

5. DIFFERENCES IN APPROACHES, DETAILS AND OUTCOMES NEED TO BE CONSIDERED

- **All the current VAD laws are working safely, but some have fewer unnecessary barriers and are more effective in meeting people's needs and wishes.**
- This section includes details of similarities and the differences between laws, with the least effective being in the US (Oregon) approach and potentially in Victoria.

6. PALLIATIVE CARE, ADVANCE CARE PLANS AND VAD – ALL ARE NEEDED NOT 'EITHER/OR'

- VAD provides an additional, last resort end of life option, not a replacement for palliative care and other improvements to end of life choice.
- This section includes links to empirical palliative care data and Palliative Care Australia reports.

1. INTRODUCTION

DwDTas has consistently argued for well-informed, principled and evidence-based decisions on voluntary assisted dying legislation, based on the best available data and evidence, reasonable assumptions and reasoned analysis and conclusions. This paper provides a relatively brief overview of the current situation involving voluntary assisted dying legislation in Australia and overseas and some key issues. It includes links to reliable, trusted sources of relevant information which are independent of DwDTas. Our aim is to support MPs to make well-informed, principled and evidence-based decisions on the next Tasmanian VAD Bill. All views and claims need to be checked against reliable independent sources of accurate, relevant, reliable information. More detailed data is available on request.

Voluntary assisted dying laws are now long established, thoroughly scrutinised laws. The number of laws is increasing because of overwhelming evidence they are needed, are working safely and are highly valued wherever they have been passed. There are **now 20 jurisdictions with a form of legal voluntary assisted dying; 16 of them with specific legislation**. New Zealand is likely to soon become the 21st.

Mike Gaffney, Independent Member in the Legislative Council, has been consulting widely on drafts of his Bill, End of Life Choices (Voluntary Assisted Dying), which he intends to move in the Parliament in August. His Bill is based on a principled and evidence-based approach and has all the components of a safe, systematic, accountable and transparent legal framework. The approach it takes is consistent with more effective laws, because it avoids unnecessary hurdles and barriers to access to VAD in other jurisdictions, particularly Victoria, such as prognoses of 6 months to live and the requirement for one of the doctors to be a specialist. DwDTas has recommended a number of improvements to drafts of the Bill.

We believe that a principled response to the issue of VAD requires acknowledgement and a response of empathy, kindness and respect for the people whose needs and wishes are not met by current options, and who are making voluntary, informed end of life choices for medically provided voluntary assisted dying (VAD) to end their intolerable and unrelievable suffering and to achieve the best end of life they can in their very difficult circumstances.

The WA inquiry report, [*My Life, My Choice*](#), identified the **two core reasons for voluntary assisted dying** legislation: *Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee's recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying.*

The major omission from commentaries against VAD is acknowledgement of both these aspects and of the people who will be eligible for medical assistance under the law. We have yet to find a single example. What is also missing from claims against VAD laws is acknowledgement of all the components of the systematic legal framework including the accountable system of independent monitoring, scrutiny and public reporting to Parliament. Many fallacious and misleading claims made about feared risks of VAD are based on poor quality, inadequate data and a misunderstanding or deliberate misinterpretation of the data, even when the claims have been refuted repeatedly by every recent, thorough review, including the Australian ones. Those reviews – and others - reached consistent, evidence-based and well-argued conclusions about the effectiveness of safeguards and prevention of risks. For example, the [*Victorian inquiry*](#) found: *The Committee is satisfied, through its research into international jurisdictions, that assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse.*

2. INCREASING ACCEPTANCE OF THE EVIDENCE - 20 JURISDICTIONS AND COUNTING

- There is an **increasing rate of acceptance by parliamentarians** of the evidence of the need for voluntary assisted dying (VAD) legislation and the effectiveness of safeguards to prevent feared risks.

- There are **20 jurisdictions with a form of legal voluntary assisted dying**, all but one in Western liberal democracies similar to ours. Over 200 million people live in the jurisdictions that have legal VAD.
- **Sixteen of those jurisdictions have specific legislation** for doctor-provided VAD, passed by democratically elected parliaments, with detailed requirements for eligibility, the significant roles and responsibilities of doctors, and the monitoring, scrutiny and reporting of assisted deaths.
 - Three in 2019 - New Jersey (US) (March 19), Maine (US) (June 19) and **WA** (Dec 19 –operative in 2021). (In November 2019, the New Zealand Parliament also passed the [End of Life Choice Act 2019](#), subject to ratification by a national referendum at the same time as Sept 2020 election.)
 - Other laws passed in chronological order: Oregon (1994 and came into operation in 1997), the Netherlands (2002), Belgium (2002), Luxembourg (2008), Washington (US) (2009), Vermont (US) (2013), California (US) (2015), Quebec Province in Canada (2015), Canada (2016), District of Columbia (US) (2016), Colorado (US) (2017), **Victoria (2017)** and Hawaii (US) (2018).
 - In three US States – Oregon, Washington and Colorado - the laws followed majority citizen ballots.
 - In two jurisdictions, Montana State in the US and Colombia in South America, legal VAD relies on court decisions. In Switzerland, the Criminal Code 1942 allows someone to assist a person to suicide as long as it is not for selfish reasons. Commercial services, such as [Dignitas](#), allow access to assisted suicide by people from many countries including Australia. Assisted suicide is legal in Germany as confirmed by a [court decision](#) in February 2020 but commercial services are not legal.
- **Over 50% of the laws have been passed in the last 4 years** and this pattern of increasing acceptance is similar to other social law reform for which there is majority support but some strong opposition.
- The first Australian State to pass VAD legislation was Victoria. The [Voluntary Assisted Dying Act 2017](#) came into operation on 19 June 2019. Comprehensive official information about the law and implementation material is available at <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying>.
- In December 2019, WA became the second Australian State with the passing of its [Voluntary Assisted Dying Act 2019](#), which will come into operation in June 2021.
- **The number of laws is likely to increase in coming years** – The [Queensland Parliamentary inquiry](#) recommended a legislative scheme for voluntary assisted dying and a Bill is being prepared by the State's law reform body; a Bill is likely in SA; Parliaments in Portugal and Spain have had recent votes to support VAD laws; and more laws are expected in other US States.

3. VAD LEGISLATION MEETS DEMONSTRATED NEEDS, WISHES AND SUPPORT ACROSS THE COMMUNITY

- The most common reasons for the laws are shown by Parliamentary and community debates and multiple thorough reviews, reports, articles and commentaries about VAD laws:
 - **to meet the needs of people with intolerable and unrelievable suffering** caused by serious, incurable medical conditions where there is no chance of recovery or improvement; and
 - **to respect people's wishes for the end of their lives and their voluntary, informed choices** made in accordance with their own beliefs, values, what is important to them and their individual circumstances.
- The evidence is very clear that, despite the best skills and efforts of doctors and other health professionals working in palliative and end of life care, **some people experience intolerable suffering that cannot be relieved adequately**. There is reliable data and expert opinion (see section 6 below) supporting this and many, many testimonials, as provided to inquiries such as the Victorian, WA and Queensland inquiries into end of life choices and in the media. There have already been many examples in the Tasmanian media and more that will be presented to the Parliament.
- There is **no evidence that doctors are providing VAD to people because they feel a burden**, or have been coerced or manipulated into requesting VAD. Most of the claims about people accessing VAD because they feel a burden are based on an inaccurate and distorted interpretation of Oregon reports.

- The evidence is very clear that **some people are taking desperate action including violent suicides** when they have serious illness and great suffering. Harrowing evidence about such suicides was provided by State Coroners to the Victorian, WA and Queensland Parliamentary inquiries into end of life options including that they constitute approximately 10% of all suicides.
- Legislation for doctor-provided voluntary assisted dying is a very rare political issue because **support is so high, higher than for any other comparable issue and the support is very high across the community - across religious and political affiliation, age groups and gender** in Tasmania and elsewhere in Australia and in other comparable countries. The [ABC Vote Compass survey for 2019](#), with 450,479 respondents, found 90% support, including 77% of Catholics, 76% of Protestants, and 71% "other religion". The [Roy Morgan poll in November 2017](#) found that 85% of national and Tasmanian respondents said 'yes' to the question: "If a *hopelessly ill* patient with *no chance of recovering* asks for a lethal dose, should a doctor be allowed to *give* a lethal dose, or not?". This is consistent with other reputable polls over many years (see our paper [Support for Voluntary Assisted Dying Law Reform](#)). Recent Tasmanian Bills reflect the wish of the community for this 'last resort' option.
- The [report of the 2018 Council on the Ageing \(COTA\) survey](#) states: *On the topic of assisted dying, overwhelming support is evident, at 84% - with results highly consistent across all states and territories. Some differences were found by religion, where support was highest among those with no religion (95%), and lowest among those who identified as Baptist (53%) or Catholic (74%).* The large majority who would investigate VAD for themselves included 57% of Catholic participants and 46% of Baptist participants. (See also [Christians Supporting Choice for VAD](#) on why Christian support is high.)
- **The proportion of doctors in Tasmania and across Australia who support and would provide VAD is not known with any certainty.** The data that is available, combined with substantial evidence from overseas experience, indicate that it is reasonable to assume that a significant proportion of our doctors support an option similar to the proposed End of Life Choices (VAD) Bill and the number of doctors prepared to provide VAD will increase over time as awareness and trust in the law increases.
- **Medical associations around the world are reviewing their policies on VAD** and many are adopting a neutral or supportive stance after extensive consultation with their members. This includes the Canadian Medical Association, which also consulted widely with the community as well as its members. The CMA provides [equal support for "conscientious participation and conscientious objection"](#) by their members under the law and has consistently advocated for patients as well as doctors.
- Organisations representing nurses generally have neutral policies on VAD eg [ACN](#), [ANMWE](#), [NSWNMA](#).
- The **Royal Australian College of GPs** (80,000 members compared to app. 30,000 AMA members) has a [Position Statement on voluntary assisted dying legislation](#), that is fair, reasonable and patient-centred.
- The **Royal Australasian College of Physicians** is the Australian medical association that has conducted the most extensive consultation process before adopting a more neutral policy on VAD. In November 2018, the College published an updated policy, [Statement on Voluntary Assisted Dying](#), which states: *The RACP respects and supports all its members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is important. The RACP recognises that legalisation of voluntary assisted dying is for governments to decide, having regard to the will of the community, to research, and to the views of medical and health practitioners.*
- The **AMA** represents about 26% of doctors nationally (2018 figures), and probably a smaller proportion in Tasmania. This should be checked with the AMA. It can only speak for this relatively small membership but the AMA 2016 survey found: *"More than half of respondents (52%) believe euthanasia [doctor-administered drugs] can form a legitimate part of medical care and 45% believe the same for physician assisted suicide [self-administration of drugs]".* A majority agreed VAD should be provided by doctors and this would not negatively affect the trust patients have in doctors. When VAD is to be provided by doctors, *"the vast majority (> 90%) supported it in the case of a person suffering an incurable illness associated with unrelievable and unbearable suffering' while less (<71%) supported it for a terminal illness"*. (More details in [AMA Review report](#))

4. VOLUNTARY ASSISTED DYING LAWS PROVIDE AN ESTABLISHED, SCRUTINISED, SAFE AND RESPONSIBLE OPTION

- Legal doctor-provided voluntary assisted dying (VAD) is now **long established, with decades of combined experience which has been subjected to rigorous, thorough scrutiny**. The earliest legislation still in operation is the Oregon *Death with Dignity Act* 1994 which began operation in 1997. Voluntary assisted dying has been provided in the Netherlands under legally sanctioned duty of care principles and court judgements for years prior to their 2002 legislation. In 2019, the laws in Victoria and Hawaii came into operation and three more were passed.
- **Multiple recent thorough reviews, including parliamentary inquiries**, have gathered a massive amount of evidence and the views of the community and experts. After carefully examining the evidence and views, the reviews and inquiries have reached **consistent conclusions about the need for, and the safety and value, of a legal VAD option**, as well as action on other end of life issues.
- The extensive 2018 WA report, [*My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices*](#), which resulted from the WA parliamentary inquiry, documents the review and presents arguments, evidence and findings and recommendations about a range of issues including VAD. It followed the [Victorian inquiry into end of life choices](#) and passing of the Victorian *Voluntary Assisted Dying Act* 2017, and numerous other reviews, chiefly in Canada. This includes by the [Canadian Supreme Court](#), the [Royal Society of Canada](#) and Parliamentary inquiries in the national and Quebec Parliaments. (See for example, the Canadian Parliament Joint Select Committee report, [Medical Assistance in Dying: A Patient-centred Approach](#).)
- Key points made in the WA report, supported by all but one member of the Committee, are:
 - *Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee's recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying.*
 - *It is clear from the evidence that even with access to the best quality palliative care, not all suffering can be alleviated. Palliative care physicians themselves acknowledge this.*
 - *Overwhelmingly, people want to live. For those left behind, the protracted death of a loved one from a terminal or chronic illness can be devastating.*
 - *How we die has changed over the last 60 years. Medicine and the law have not kept pace with this change, nor with changes in community expectations.*
 - *Having weighed the evidence, the committee concurs with findings by similar parliamentary inquiries in Victoria and Canada that risks can be guarded against and vulnerable people can be protected.*
 - *Those who fundamentally oppose the introduction of Voluntary Assisted Dying lack rigorous evidence to back up their claims. They will inevitably criticise this process.*
- The WA Committee carefully examined overseas practices and claims based on fears about the risks of VAD legislation. It found: **“there is no evidence that vulnerable groups, including people with disabilities, are at heightened risk of assisted dying”**; no evidence to suggest the slippery slope has occurred in the jurisdictions that have legislated for voluntary assisted dying; and **“reports of suicide contagion are not supported in the evidence”**. The Victorian and other reviews reached similar conclusions. None of the reviews have found evidence that VAD laws have reduced trust in doctors or have had negative effects generally on doctor-patient relationships. No evidence has been found of a negative impact on palliative care practices and services or support for ongoing improvements - in fact the opposite. Despite such consistent evidence-based findings, opponents of VAD laws continue to ignore them and to repeat baseless fears about VAD laws.
- The [Queensland Inquiry into voluntary assisted dying](#) reported on VAD on 31 March 2020 with similar findings and evidence, and made detailed recommendations on a VAD law in that State. A Bill is being prepared by the State's law reform body.

5. DIFFERENCES IN APPROACHES, DETAILS AND OUTCOMES NEED TO BE CONSIDERED

- All recent, thorough reviews, such as the Victorian and WA inquiries, have found that existing voluntary assisted dying systems are working safely, without the feared abuses or risks to certain groups considered vulnerable to manipulation and coercion. However, there are **significant differences, as well as similarities, in their legal requirements and in their effectiveness in meeting the needs and wishes expressed by the community**. The details of these differences have received limited attention in the Australian inquiries but they are relevant and important in determining what is the most effective, as well as a safe, law here. An effective law will meet the needs and wishes of the Tasmanian community and be practical and workable in the Tasmanian situation. We will explain why we believe the Canadian model and not the US/Oregon approach is most suitable for Tasmanians.
- **All the current VAD laws are working safely, but some have fewer unnecessary barriers and are more effective in meeting people's needs and wishes.** There are two broad models of legislation, the US model and the Canadian/European model. The Victorian law is closer to the restricted US model than the Canadian model. This makes it the "most conservative" VAD legislation, as claimed by the Victorian Premier, but may also make it one of the least effective approaches. There are some differences between the Canadian and European laws.
- **Assisted deaths are a very small proportion of all deaths under all laws**, but particularly low under the least effective laws in US States eg in Oregon reaching 0.52% of all deaths in Year 22 - [2019 report](#). In [Belgium in 2018](#) they were 2% of all deaths and 4.4% in the Netherlands ([2018 report](#)). The Canadian law commenced in June 2016 and [the latest report for 2019](#) shows assisted deaths were 2% of all deaths with a steady growth in cases since 2016 due to greater awareness and acceptance. [The report on the first 6 months operation of the Victorian VAD Act](#) showed 52 Victorians had received VAD (0.24% of all deaths in the period).
- Data shows that **there are similarities in who accesses VAD, regardless of the differences between the laws**. The major reason for people accessing VAD is intolerable/unbearable suffering. In over 90% of voluntary assisted dying, the underlying conditions causing the suffering are cancer, neuro-degenerative (such as motor neurone disease), respiratory, cardio-vascular conditions or a combination of conditions. The average or median age is over 70 with only 1 - 2% under 40. Male/female assisted dying is close to 50/50. DwDTas can provide on request detailed, up to date data across a number of jurisdictions including Oregon, Netherlands, Belgium and Canada. The first Victorian report did not include detailed data but it is hoped that future ones will.
- The eligible medical condition is a core aspect of all VAD legislation in determining who will and who will not have access to legal doctor-provided VAD. There is a great deal of misinformation and misunderstanding about the differences:
 - **Terminal illness and a timeframe prognosis have never been requirements in the Netherlands, Belgium and Luxembourg, and they are not requirements in the Canadian or Quebec Province laws.** Eligibility requirements include serious medical conditions and intolerable/unbearable suffering which may result from serious chronic, neuro-degenerative as well as terminal conditions. People access VAD because of the seriousness of their condition and of the suffering that results from their total circumstances, not because they have a particular medical condition.
 - Amendments are currently being debated In Canada, following a court judgement, to ensure that people who meet all the other criteria (including intolerable suffering) may access VAD (called medical assistance in dying – MaiD) even if their deaths are not "reasonably foreseeable". They will have to meet more requirements than people whose deaths are foreseeable.
 - **Until the Victorian and WA laws, US laws were the only ones requiring a prognosis of 6 months or less to live. US laws do not have a suffering requirement** and the prognosis requirement is due to restricted US Medicaid funding for people to access affordable 'hospice' treatment available when they have a prognosis of only 6 months or less to live. This is not an issue in Australia and neither the Victorian or WA inquiries recommended prognoses be a requirement. The WA report states: "a prescribed time is too restrictive and cannot be clinically justified".

6. **PALLIATIVE CARE, ADVANCE CARE PLANS AND VAD – ALL ARE NEEDED NOT ‘EITHER/OR’**

- It's a case of both VAD and palliative care, not 'either/or'. The same can be said for improved advance care planning. **VAD provides an option for people who are still competent to express their wishes.** Advance care directives or enduring guardianships come into effect **when people are no longer capable of expressing their wishes.** DwDTas has worked for many years to encourage and assist people to do their end of life planning and make their wishes known. (See [our Guide](#))
- VAD is not a replacement for palliative and other end of life options that work effectively to meet most people's needs and wishes. **DwDTas supports doctor-provided voluntary assisted dying that provides a 'last resort' option for a small proportion of competent adults for whom current options don't work adequately.** That is, it enables them to achieve an end to intolerable suffering, that is otherwise unrelievable, through voluntary assisted dying - when, where and with whom they choose. This meets the needs and wishes of those who will never again be free of intolerable suffering and the devastating effects of their serious, incurable medical condition. **A 'last resort' approach acknowledges the importance of palliative care and other end of life care,** and doctors are required to provide information on palliative care and other options.
- We are very fortunate to have high-quality palliative care in Tasmania, which DwDTas supports very strongly. Many people are assisted by palliative and other end of life care that meets their wishes and circumstances. It is essential that improvements continue in the number and quality of palliative care services in Tasmania, including better home-based care. But, as the respected Tasmanian Professor of Palliative Care, Michael Ashby, commented in his evidence to the 2016 House of Assembly Inquiry into Palliative Care: *There isn't a single area of medicine that has a 100 per cent score, so why would palliative care be any different? Any claims by us that we can relieve all pain are patently nonsense. I think it is very foolish of certain people in our specialty around the world to convey the impression that they can. I don't think anybody these days would make that claim. What I can say is that we can nearly always make a difference for the better.* (p51 of the [Inquiry Report](#)). (Our emphasis)
- In Australia reliable data exists in the detailed reports that are provided by over 100 palliative care services to the [Palliative Care Outcomes Collaboration](#). Their reports, including [the latest national report \(Jul - Dec 19\)](#), demonstrate the significant achievements of and improvements in palliative care services across the country. They also confirm Professor Ashby's expert assessment and the evidence that has been provided to multiple inquiries that there are limitations on what palliative care is achieving and can achieve in the foreseeable future. For example, there is a PCOC benchmark that 60% of patients with moderate to severe suffering will have that reduced to mild or absent suffering. This is not being met by most services, despite their best efforts. As the PCOC concludes, "around 5% of people experience severe distress", especially from fatigue and breathlessness. In Professor Ashby's 2016 paper, [How we die](#), provided as evidence to the House of Assembly Inquiry into Palliative Care, he reports that the PCOC data showed that in Tasmania at that time "approximately 50 per cent of patients who have an episode of moderate/severe pain at the beginning of an episode of palliative care will report no pain at the end of the episode of care".
- Palliative Care Australia received two important reports on VAD in relation to palliative care which have informed their [new guiding principles](#) that take a neutral position on VAD laws in Australia. The report, [Experience internationally of the legalisation of assisted dying on the palliative care sector, October 2018](#) found: *An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced. Where jurisdictional data is available, there are consistently high levels of patient involvement in palliative care services at the time of the death through assisted dying*. (p5). [Reflections and Learnings: Assisted Dying in Canada and the United States, November 2018](#) provides valuable first-hand observations from people with experience where VAD is legal and can help to inform the law and its implementation here.

Data on VAD legislation in 5 jurisdictions

Comment: Decisions on VAD legislation need to be made on the basis of the best available evidence. This data shows that while there are similarities between jurisdictions, eg gender, age profiles and underlying medical conditions, there are significant differences. The most important of the differences is in the effectiveness in meeting the needs and wishes of people at the end of their lives. The US model helps very few people for a variety of reasons, including the restrictive prognosis requirement of less than 6 months to live.

Jurisdiction	Oregon (US)	Netherlands	Belgium	Canada	Victoria
Legislation	<i>Death with Dignity Act 1994</i>	<i>Termination of Life on Request and Assisted Suicide Act 2002</i>	<i>Act on Euthanasia 2002</i>	<i>An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) (2016)</i>	<i>Voluntary Assisted Dying Act 2017</i>
Year of commencement of law	1997	2002	2002	2016	2019
Prognosis of death to occur within specific period	"Incurable and irreversible disease" that will "produce death" in 6 months or less	No	Not for adults but it is a requirement that those under 18 have a "terminal condition"	No. Until amendment legislation is passed later this year, death needs to be "reasonably foreseeable" ¹ .	Yes – condition "will cause death" and within 6 months (or 12 months for neuro-degenerative conditions)
Intolerable/unbearable suffering requirement	No suffering requirement	Yes	Yes	Yes	Yes
Population (2018)	4 million	17 million	11.4 million	37 million	6.3 million
Report from which statistics taken ²	2019 (Year 22 report) ³	2018 ⁴	2018 ⁵	2019 ⁶	19 Jun – 31 Dec 2019 ⁷
No of assisted deaths in the reporting period and percentage of all deaths ⁸	188 0.52% of all deaths ⁹ (Total no. since 1997 – 1657; % not reported)	6,126 4.4% of all deaths	2,357 2.1% ¹⁰ of all deaths	5,631 2% of all deaths	52 (in app 6 months) Not reported but estimated as 0.24% ¹¹
Men, Women	111 men, 77 women ¹² 59% /41% (Total since 1997: 52.3%/47.7%)	3191 men, 2935 women 52%/48%	1113 men, 1244 women 47.2%/52.8%	50.9% men, 49.1% women	Not reported

Jurisdiction	Oregon (US)	Netherlands	Belgium	Canada	Victoria
Administration of the drugs	All self-administered ¹³ – 188	Doctor-administered – 5898 (96%) Self-administered – 212 (3.4%) Combination ¹⁴ – 16 (0.6%)	Not reported but it appears almost all are doctor-administered ¹⁵	Doctor or nurse practitioner administered ¹⁶ - Approx. 5624 (99.8%) Self-administered – “fewer than 7 cases reported”.	Dr-administered – 9 ¹⁷ (17%) Self-administered – 43 (83%)
Age profiles of those who accessed assisted deaths under the relevant legislation	Median age 74 ¹⁸ (Total since 1997 – 72) 74.5% aged 65 or older (Total since 1997: 73.1%) Includes 45% over 75 (28.7% between 75 – 84, 16.5% 85 and over) (Total – 43% over 75 - 27.2% 75 – 84, 15.8% 85 and over) 22.9% between 45 and 65 (Total since 1997: 24.4%) 2.6% aged under 45 (Total since 1997: 2.5%)	No information on median or average age 64% aged 70 or over (3990) Includes 31.8% 80 or over (23.5% 80 – 90, 8.3% 90 and over) 34.9% between 40 and 70 1.1% aged under 40 including 3 aged between 12 and 17 ¹⁹	No information on median or average age 67% aged 70 or over (1581) Includes 41% 80 or over (29.9% 80 – 89, 10.6% 90 – 99, 0.4% (10 people) 100 or over) 31.3% between 40 and 70 1.7% aged under 40 including 0 aged under 18 ²⁰	Average age – 75.2 years 77% aged 66 or over (4,342) Includes 47% over 76 (2,643, includes 534 over 91) (46% were between 65 and 80) 36% between 46 and 70 (1832) 1.8% aged under 46 (103)	No information reported

Underlying medical conditions causing the suffering of those who accessed legal voluntary assisted dying under the relevant legislation - percentage of assisted deaths and numbers					
Jurisdiction	Oregon (US)	Netherlands	Belgium	Canada	Victoria
Cancer ²¹	68.1% (128) (Total since 1997: 1244-75.1%)	66% (4,013)	61.4% (1447)	67.2%	
Neurological/neuro-degenerative	13.8% (26 ²²) (Total since 1997: 187 – 11.3%)	6.2% (382 ²³)	8.3% (195)	10.4%	
Cardio-vascular/circulatory	4.8% (9) (Total since 1997: 76 – 4.6%)	3.7% (231)	3.8% (89)	10.1%	
Pulmonary/respiratory disorders	7.4% (14) (Total since 1997: 89 – 5.4%)	3% (189)	2.4% (57)	10.8%	
Combination ²⁴		12% (738)	18.6% (438)	9.1%	
Combined total of these main conditions	94.1%	90.6% (as reported²⁵)	94.5%	Exceeds 100% because providers able to select more than one condition	
Other	5.9% includes: <ul style="list-style-type: none"> Gastrointestinal disease [e.g., liver disease] – 1.6% Endocrine/metabolic disease [e.g., diabetes] – 1.1% Other illnesses²⁶ – 3.2% 	9.4% includes: <ul style="list-style-type: none"> Psychiatric disorders²⁷ - 1% (67) Multiple geriatric syndromes²⁸ - 3.3% (205) Dementia - 2.3% Other²⁹ - 2.6% (158) 	5.5% includes: <ul style="list-style-type: none"> Mental and behavioural disorders - 2.4% (57) Other³⁰ – 3.1% 	6.1% includes: <ul style="list-style-type: none"> “a range of conditions, with frailty commonly cited” and 4.6% - “Other organ failure”	

Medical or nurse practitioners who provide VAD – reported differently in different jurisdictions					
Jurisdiction	Oregon (US)	Netherlands	Belgium	Canada	Victoria
	Not reported	85% - General practitioner (5194) 5% - Elderly care specialist (294) 5% - Specialist working in a hospital (293) ³¹	59.1% - general practitioner or trained medical practitioner provider of VAD 34% - specialist 6.8% - palliative care	65% - Family medicine 9.1% Palliative medicine 7.1% Nurse practitioner ³²	Not reported ³³

Additional data provided in reports and other key studies:

- **Oregon Annual Reports:** Other interesting data reported includes:
 - Other characteristics of patients who have died from DWDA [Death with Dignity Act] ingestions: race (96% white in 2019); marital status; education (close to 80% with post school education); residence county/region; hospice enrolment (90% in 2019) and health insurance status; underlying illness – types of cancer, illnesses other than the main four; where patient died (94% at home in 2019); end of life concerns; whether health care provider present; complications; timing of DWDA event (eg time between ingestion and death – some very long periods indicate the very unsatisfactory drug situation in the US).
 - a comparison of the number of prescriptions and assisted deaths. Approximately 1/3 of people who are eligible for VAD and receive a prescription for the lethal drugs do not use it.
 - “Medications used in DwDA ingestions”. The cost and availability of suitable drugs for assisted deaths are a major problem in the US but not elsewhere. (See for example, “How much does the medication cost?” at <https://www.deathwithdignity.org/faqs/>)
 - ‘End of life concerns’ - This data is often misrepresented as the patients’ “reasons” for choosing VAD but it is not. The data is not collected from patients but from doctors, and reports whether the doctor believes any of a limited list of concerns contributed to the patient’s request for VAD. (See [form that must be completed by doctors](#)). Doctors believe these are the most common concerns that contributed to their patients’ requests for VAD since the law came into operation in 1997: doctors believe that for 90.2% of patients “his or her terminal condition representing a steady loss of autonomy” was a concern that contributed to their requests for VAD; for 89.3% of their patients “the decreasing ability to participate in activities that made life enjoyable” was a concern that contributed to their requests for VAD ; and “a loss of dignity” was a concern for 74% of patients.

The most frequently misrepresented and distorted data relates to the issue of “burden”. Doctors are asked to report if they believe a concern about “the physical or emotional burden on family, friends, or caregivers” contributed to their patient’s request for VAD. This is not whether the patient feels

a burden. Doctors reported that, for less than half of their patients who chose VAD (47%), a concern about **the** physical or emotional burden on family, friends, or caregivers was even one of the concerns that contributed to their patients' requests.

- **What is known about how close to death people who use VAD are?**

Data is limited, but good quality data is available, on how close people who use VAD are to when they are likely to have died, adding to many testimonials and anecdotal evidence. The data that is available indicates that the vast majority of people who use VAD are very close (days and weeks) to when they would have died. This means that the choice of VAD shortens people's lives by very little. It is this characteristic that makes it so different from premature suicides, especially of young people, when lives may be shortened by decades. It is also reasonable to assume that VAD is a 'last resort' choice that is held off as long as possible. This needs to be taken into account in the procedures and demands on the people who are eligible for VAD.

Belgium – Under the Belgian law, there are additional requirements if doctors believe the people making requests for VAD are not likely to die in the near future (*Attendu à brève échéance*). Official reports include details of those expected to die in the near future and those not expected to die in the near future. The vast majority of those who receive VAD are expected to die in the near future. In 2018, 85.4% of total VAD numbers (2012 people) were expected to die in the near future. Of the 345 who not expected to die in the near future, 152 (44%) had "multiple pathologies" and 70 (20%) had neurological conditions, ie conditions which can cause intolerable suffering over a prolonged period and potential loss of decision-making capacity before people get close to death.

The Netherlands –

As well as the official annual reports in the Netherlands, there has been a respected, academic peer-reviewed, longitudinal study reporting every five years. It examines death certificates to determine the incidence and changes in end of life practices including euthanasia, assisted suicide, ending of life without explicit patient request, intensified alleviation of symptoms (eg increased pain relief), forgoing of life-sustaining treatment (eg withdrawal from or refusing treatment such as dialysis, more chemotherapy), continuous deep sedation (also called "palliative or terminal sedation" in the report and in Australia) and patient deciding to end life by stopping eating and drinking.

The report of the 2010 study was published in the Lancet in 2012 - [Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey](#) – as a nationwide death-certificate study that was largely similar to earlier studies done in 1990, 1995, 2001, and 2005. The report for 2010 reports doctors' views that 41% of those who died as a result of "euthanasia and physician-assisted suicide" died within a week of when they would have done.

The similar study in 2015 was reported on in [a letter to the New England Journal of Medicine](#) on 3 August 2017 (behind a paywall but we have a copy). It is relatively brief. It concluded that the percentage of patients who received "physician assistance in dying" who had an estimated life expectancy of more than a month increased between 2010 and 2015 from 16% to 27%, but provided no comment on why that was the case.

Other conclusions included:

- *About half of all requests for physician assistance in dying were granted in 2015.* [In other words, doctors found after a thorough assessment that the people did not meet the eligibility requirements, had withdrawn their requests or had not completed all the required processes.]
- *In 2015, physicians who responded to a survey (with more than one possible option) indicated that 92% of the patients who received physician assistance in dying had a serious somatic³⁴ disease; 14% had an accumulation of health problems related to old age, and a small minority had early-stage dementia (3%) or psychiatric problems (3%)*
- *Ending of life without an explicit patient request decreased, from 0.8% in 1990 to 0.3% in 2015.* [This is a separate end of life practice of doctors that occurs in other countries as well as Australia as shown by academic studies³⁵, eg Neil et al. It is not caused by VAD.]

More details are included in the [third evaluation](#) of the *Termination of Life on Request and Assisted Suicide Act 2002* which is a lengthy report in Dutch, which includes a summary in English within the report. The summary reports some of the findings of the longitudinal study in 2015:

- “Incidences of other medical end-of-life decisions in 2015 were comparable with those in 2010. This is not the case for palliative sedation: the incidence increased from 12% in 2010 to 18% in 2015.”
- “the percentage of patients for whom the estimated shortening of life is longer than half a year is never more than 10%”
- 73% likely to have died in less than a month, 27% longer than a month.

It has also been reported in a 2019 article in the Medical Journal of Australia by respected Australian and Dutch academics³⁶ that: *In the Netherlands, although patients need not be terminally ill to be eligible, the majority of patients who receive euthanasia or physician-assisted suicide have a short estimated life expectancy: a week or less for 36%, 2–4 weeks for another 36%, 1–6 months for 19% and more than 6 months for 8%. Another study showed that for over half of patients (62%), the time between the first explicit request and the time of administering euthanasia or assisting in suicide was 1 month or less. Dutch data also reveal that for about a quarter of all euthanasia requests, the patient died before the physician decided whether or not to grant the request or between granting the request and performing euthanasia.* (See article for references for data.)

Why is self-administration so low when laws allow both self-administration and doctor-administration of VAD drugs?

The same 2019 article in the Medical Journal of Australia by respected Australian and Dutch academics reported: *In the Netherlands, while both euthanasia (practitioner-assisted) and assisted suicide (self-administration) is permitted, the incidence of self-administration is very low. In 2017, 6306 cases of euthanasia, 250 cases of assisted suicide, and 29 cases involving a combination of both were reported to review committees in the Netherlands. Indeed, the guidelines of the Royal Dutch Medical Association originally indicated a preference for assisted suicide because it confirmed the patient request, but ultimately omitted this because it did not happen in practice. Practitioner administration is preferred in the Netherlands for a range of reasons. First, about half of the patients are too weak to self-administer. Second, doctors prefer to control the process or take responsibility for effective provision of VAD. Third, and related to the second reason, complications occur more frequently in*

self-administration; in about 10% of cases there are technical difficulties, such as difficulty in swallowing, and in about 9% of cases there are complications such as vomiting. As a final point of contrast, the Dutch guidelines state that if self-administration fails (eg, the patient cannot finish the drink, vomits or does not die within a certain time frame), the doctor has an obligation to administer the medication. Some of the 29 reported cases of a combination of assisted suicide and euthanasia in 2017 are likely to be such cases. (See article for references for data.)

Issues related to oral ingestion of VAD drugs have received consideration in Canada. Findings and recommendations are made in two documents – “The Oral MAiD Option in Canada; Part 1: Medication Protocols” and “Part 2: Processes for Providing”³⁷.

END NOTES

¹ S.241.2(2)(d) “their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining”. An [amendment Bill](#) is currently being debated in the Canadian Parliament to also allow MAiD (medical assistance in dying) for those whose deaths are not reasonably foreseeable but under stricter conditions. There are also other changes being made, eg “to permit medical assistance in dying to be provided to a person who has been found eligible to receive it, whose natural death is reasonably foreseeable and who has lost the capacity to consent before medical assistance in dying is provided, on the basis of a prior agreement they entered into with the medical practitioner or nurse practitioner”. Further details are in the Bill and at <https://www.justice.gc.ca/eng/csj-sjc/pl/ad-am/index.html>.

² It is important to note that statistics can vary from year to year. Only the Oregon annual report provides total data since 1997, the first year of operation, which provides a better indication of the data.

³ <https://www.deathwithdignity.org/news/2020/03/2019-report-on-oregon-death-with-dignity-act/?fbclid=IwAR3dxtJ2PDagtqEO9HrzbR5ztpCpKRqY1mAHQiBTjdYTKTOcAN8KvTVQ>

⁴ Available at <https://english.euthanasiecommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports>

⁵ Data for 2018 is from a [media release by la Commission fédérale de Contrôle et d’Évaluation de l’Euthanasie](#). Data is usually reported officially in a biennial report, the last of which is for the years 2016 and 2017 - <http://organesdeconcertation.sante.belgique.be/fr/documents/cfcee-rapport-euthanasie-2018>. This report is available in French.

⁶ [First Annual Report on Medical Assistance in Dying in Canada 2019](#). Four interim reports have previously been issued before a comprehensive one that will now be issued annually.

⁷ Available at https://www.parliament.vic.gov.au/file_uploads/FINAL_VADRB_Report_of_operations_2019-2020_20200210_002_GD3MDJj6.pdf. The first Annual Report is due to be issued on 19 August 2020.

⁸ In Tasmania in 2019 there were 4654 registered deaths (Source: <https://www.justice.tas.gov.au/bdm/statistics>). 1% = 46.5; 0.5% = 24

⁹ Other US States seem to have an even smaller percentage of total deaths. Although not reported in its annual report, Washington State (the second state to have VAD legislation from 2009) assisted deaths in 2018 appear to be 0.4% of total deaths. California has had legislation since mid-2016 and in 2018, as reported in its annual report, assisted deaths were 0.13% of all deaths.

¹⁰ Calculated on the basis of total deaths in Belgium in 2018 – 110,645 (<https://www.statista.com/statistics/516846/number-of-deaths-in-belgium/>)

¹¹ Total deaths Jul – Dec 2019 22,203 Source: [Victorian death statistics](#)

¹² This is different from the norm, eg in 2018 it was 87 men and 81 women (or 52%/48%). The total percentage is a much better indicator.

¹³ There is no provision for doctor administration of the drugs, even if the person cannot physically ingest the drugs or even if complications occur.

¹⁴ According to the report: *“A combination of the two occurs if, in a case of assisted suicide, the patient ingests the lethal potion handed to them by the physician, but does not die within the time agreed by the physician and the patient. The physician then follows the usual procedure for termination of life on request, by intravenously administering a coma-inducing substance, followed by a muscle relaxant.”* (page 13)

¹⁵ Only 0.2% of assisted deaths in 2018 involved oral barbiturates.

¹⁶ The Canadian legislation provides nurse practitioners with the same status as doctors in relation to MAiD and the assisted dying drugs can be administered by a doctor or a nurse practitioner, or self-administered. Under the Quebec legislation, only doctor-administration is legal (ie no self-administration or nurse practitioner administration). The vast majority of assisted deaths are provided by doctors. In 2019 there were 2421 doctor administered assisted deaths (93%), with nurse practitioners providing 193 or 7%.

¹⁷ The Victorian VAD Act requires self-administration with doctor-administration only if the person is physically incapable of the self-administration or digestion of the VAD drugs.

¹⁸ This means as many under 74 as over 74.

¹⁹ The Netherlands' legislation has allowed euthanasia for 12 – 17 year-olds as well as adults since it was first introduced. The numbers under 18 have been and remain extremely small.

²⁰ After a lengthy community debate, the Belgian Parliament voted in Feb 2014 to amend their legislation to allow euthanasia for those aged under 18, but with more restrictive conditions than for those over 18. Those under 18 must have a terminal condition and unbearable and unrelievable suffering - “The child must be in a ‘medically futile condition of constant and unbearable physical suffering that cannot be alleviated and that will result in death in the short term’ (Euthanasia Act 2002, section 3§1). The child must also display the ‘capacity of discernment’ and be ‘conscious at the moment of making the request.’ (Euthanasia Act 2002, section 3§1). In addition, the child’s decision must be supported by a parent or legal guardian who has a right of veto.” (<http://diversityhealthcare.imedpub.com/children-and-euthanasia-belgiums-controversial-new-law.php?aid=3729>). The first death under this provision was in 2016 (a 17 year-old), there was another 1 in 2016, 1 in 2017 and 0 in 2018.

²¹ According to an article by Penny Egan, CEO Cancer Council of Tasmania (Mercury 1 July 2020): “The most recent statistics show Tasmania had 3480 new cases of cancer in a year and 1266 cancer-related deaths. That’s more than nine people a day receiving a cancer diagnosis. We all know someone who has been diagnosed with cancer and the devastating effects on the person, their family and friends. The risk increases with age — 50 per cent of us will be diagnosed with cancer by 85. Tasmania has the second highest cancer rate in Australia for mortality and diagnoses.”

²² The majority (19 out of 26) were suffering from amyotrophic lateral sclerosis (ALS) which we call motor neurone disease.

²³ “Such as Parkinson’s disease, multiple sclerosis and motor neurone disease”

²⁴ Netherlands reports “Combination”, Belgium reports “Polypathologies” or multiple pathologies and Canada reports “Multiple comorbidities”.

²⁵ 90.6% of the cases (5,553) involved patients with: - incurable cancer (4,013); - neurological disorders, such as Parkinson’s disease, multiple sclerosis and motor neurone disease (382); - cardiovascular disease (231); - pulmonary disorders (189); or - a combination of conditions (738) (p 13; 2018 report)

²⁶ Other illnesses in 2019 included arthritis, arteritis, blood disease, complications from a fall, kidney failure, musculoskeletal system disorders, sclerosis, and stenosis

²⁷ Netherlands reports “psychiatric disorders”; Belgium reports “Troubles mentaux et du comportement” (mental and behavioural disorders)

²⁸ Netherlands - *Multiple geriatric syndromes – such as sight impairment, hearing impairment, osteoporosis, osteoarthritis, balance problems or cognitive deterioration – may cause unbearable suffering without prospect of improvement. These syndromes, which are often degenerative in nature, generally occur in elderly patients and are the sum of one of more disorders and related symptoms. In conjunction with the patient’s medical history, life history, personality, values and stamina, they may give rise to suffering that the patient experiences as unbearable and without prospect of improvement.* [p15 of 2018 report]

²⁹ Includes “conditions that do not fall into any of the above categories, such as chronic pain syndrome”

³⁰ The report lists a range of other illnesses all less than 1% of assisted deaths, eg Diseases of the osteo-articular system, muscles and connective tissue (0.9%); Traumatic injuries, poisonings and certain other consequences of external causes (0.5%); Diseases of the digestive system (0.5%) and Diseases of the genitourinary system (0.3%).

³¹ See page 16 of the 2018 report for more details.

³² See p29 of the 2019 report for more details of other medical categories proving MAiD.

³³ In Victoria, unlike any other VAD legislation, implementation guidelines require specialist qualifications for at least one of the two doctors involved in the assessment process, even though the legislation is not that specific. The law states in S10(3) – Either the co-ordinating medical practitioner or each consulting medical practitioner must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed. This is causing major and cruel delays for people in some parts of the State and with some conditions, eg motor neurone, requiring a Neurologist. See <https://www.theage.com.au/national/heart-achingly-painful-allan-waited-for-100-days-before-being-granted-permit-to-die-20200619-p554az.html>. WA avoided this unnecessary restriction on the basis of arguments by the RACGP - <https://www1.racgp.org.au/newsgp/professional/gps-outraged-at-suggestion-of-inadequate-expertise?fbclid=IwAR3I9-KvtIDLW6ELNy5vBuRlg-W49JGvYcwrpq1GiUNK25rf2o-xrlMjjEo>

³⁴ That is relating to the body, as distinct from the mind.

³⁵ For example, Neil et al, ‘End-of-life decisions in medical practice: a survey of doctors in Victoria (Australia)’, J Med Ethics. 2007 December.

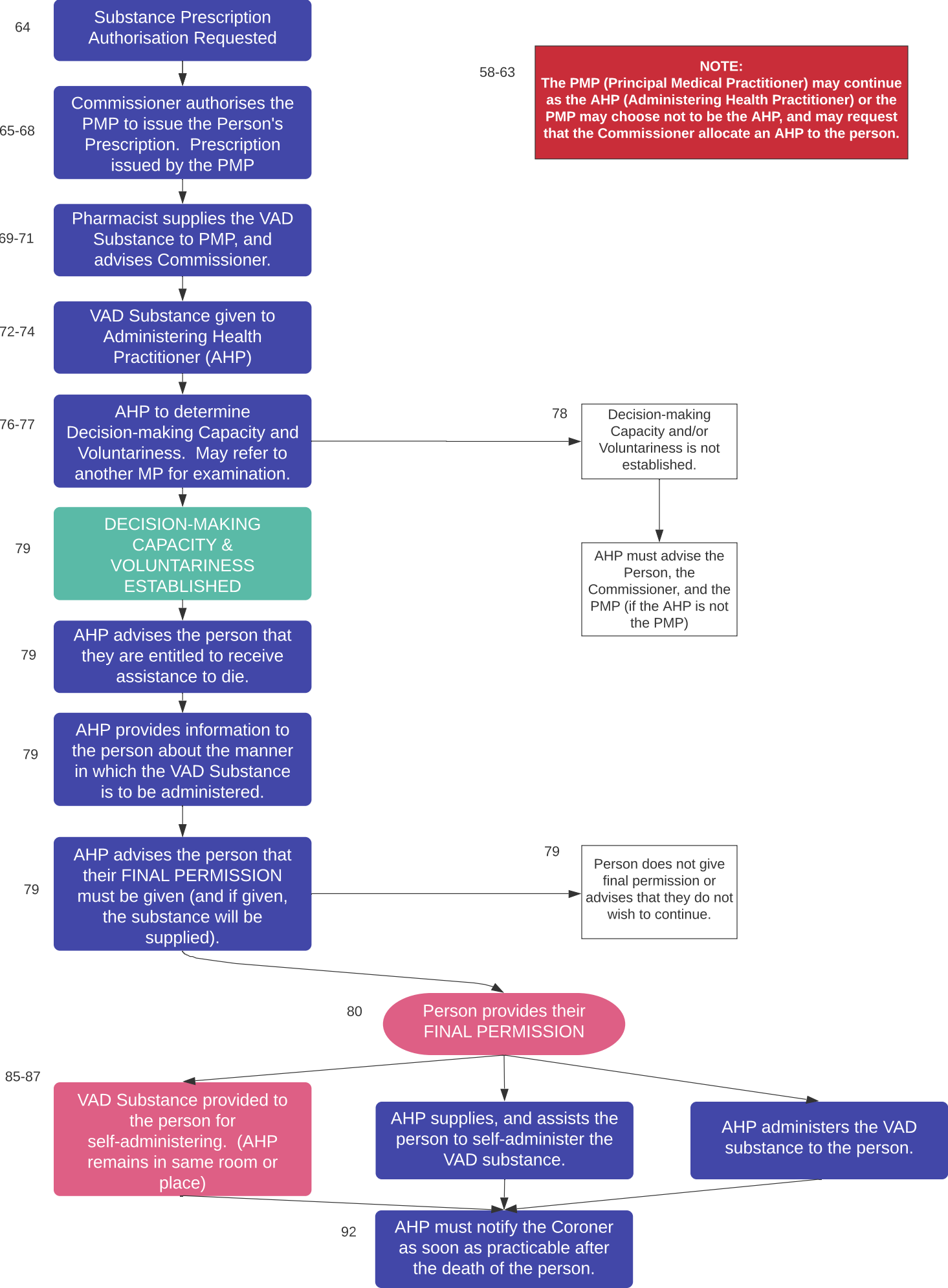
³⁶ P 438 Bregje Onwuteaka-Philipsen, Lindy Willmott and Ben P White, *Regulating voluntary assisted dying in Australia: some insights from the Netherlands*, Med J Aust 18 November 2019 (Published online: 9 September 2019) Available at <https://onlinelibrary.wiley.com/doi/epdf/10.5694/mja2.50310>.

³⁷ <https://camapcanada.ca/wp-content/uploads/2019/01/OralMAiD-Med.pdf>; <https://camapcanada.ca/wp-content/uploads/2019/01/OralMAiD-Process.pdf>

END-OF-LIFE CHOICES (VOLUNTARY ASSISTED DYING) BILL 2020 - Simplified Flow Chart



END-OF-LIFE CHOICES (VOLUNTARY ASSISTED DYING) BILL 2020
Administering Health Practitioner (AHP) Pathway



END-OF-LIFE CHOICES (VOLUNTARY ASSISTED DYING) BILL 2020

Private Self-Administration Pathway

