

Tips on having your voice heard

Write an email or letter, pick up the phone, visit your MP.

Your State Parliament may soon debate a Voluntary Assisted Dying Bill. Let your MPs know your thoughts. Also discuss the issue with your family and friends and ask them to contact their MPs as well. We each only have one chance to be heard. Remember, approximately **85% of Australians want this law passed**. Our politicians must hear this message.

Write to or call your local politicians

Look up your MP's contact details on our website, using our [MP Lookup Tool](#).

1. In a letter, include your address and the date.
2. Use your local MP's name.
3. State simply at the beginning WHY you are writing to them.
4. Personal stories are powerful.
5. Sign your letter and print your name (include your phone number if you wish).

What you could say:

"I am contacting you to let you know that I strongly support the new voluntary assisted dying laws."

"I want my own choice on how I die if I have extreme suffering and there is no hope of recovery or respite."

"As my MP I would like you to respect the view of the majority of your constituents"

Visit your state MPs in their office

Call your local MP's offices and request an appointment. They are your elected representative and are obliged to try and make time to see you. Find their office location using our [MP Lookup Tool](#).

1. Call and request an appointment.
2. If the office can't offer a time, ask what hours the office is open.
3. Drop in and tell the staff your message in person.

What you could say:

"I want to tell you personally my thoughts because this is very important to me."

"I want my own choice on how I die if I have extreme suffering and there is no hope of recovery or respite."

"We are constituents and expect our elected representatives to vote as the majority requests."

Organise a bus trip to your local MPs' offices - and tell the local newspaper

Strength in numbers! Organise an appointment and take the bus. You should be seen as you are all local constituents.

1. Call and request an appointment – explain you have a bus-load of voters.
2. Book a bus or take the local service.
3. Ask your friends and neighbours to join you.

Learn more and connect on social media

For more information, including the latest publications, news and other resources, visit our website:

www.GoGentleAustralia.org.au

Find us on:

[Facebook](#), [Instagram](#) and [Twitter](#).

Thank you for your support.

A guide to telling your story



Writing down your experiences, especially when they relate to grief, can be tricky. Where do you start?

Here are some suggestions to help you tell your story.

1. Who was the person you are writing about? Imagine sitting down with a friend who has never met this person. What would you tell them to paint a picture? Start with their name and what relationship they were to you.
2. Tell us something about their life that was important to them and to you. For example, their career, their hobbies, their hopes and dreams.
3. When did they first become ill? How did the diagnosis of their terminal illness come about and what was their reaction?
4. What happened in the period between diagnosis and death? For example, how did they cope? Were there memorable moments (happy or sad)? Did they discuss their end of life with you and others? What were their plans, hopes and fears?
5. Where were they treated and what treatments did they receive? If applicable, the name of the institution and location.
6. When and how did the person die? Was there a difference between what you/your loved one was told would happen and what actually happened?
7. Did you provide any feedback to the team/institution who were caring for the person and, if so, how did they respond?

It is helpful for any story to include these elements. However, include more information if you think it is appropriate.

If your experience was traumatic, please be aware that writing about it can be helpful but it can also bring up strong emotions. These may be directly connected and perfectly understandable (for example crying while you write) but they may also surface at unexpected moments and be difficult to reconcile (for example bursting into tears at the bus stop, or becoming angry at little things for no apparent reason).

If at any moment you struggle with these experiences, please reach out for help. Your GP can refer you to a local counsellor or you can call **Lifeline** on **13 11 14** (24 hours a day).

Voluntary Assisted Dying

Frequently asked questions

Why do we need a Voluntary Assisted Dying law?

Simply, too many terminally ill Australians are dying bad deaths, denied the choice to decide when they have suffered enough at the end of life.

Since 2016, Australia has 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 – came to the same conclusions:

- Even the best palliative care cannot relieve all suffering for terminally ill patients;
- Doctors and nurses are delivering inadequate pain relief to dying patients for fear of breaking the law;
- Family and friends are being traumatised as they watch loved ones die agonising deaths;
- Doctors are breaking the law to assist patients suffering untreatably to die – but having to do so in secret, without consultation, oversight, or regulation;
- Elderly and terminally ill people are taking their lives, often in horrific circumstances.

All three inquiries found Australia's existing end-of-life laws to be inadequate. All recommended, by a clear majority, that Voluntary Assisted Dying be legalised as part of a broader approach to better end-of-life care including more resources for palliative care.

Is Voluntary Assisted Dying the same as Euthanasia?

The terms refer to similar, but distinct, processes.

Voluntary Assisted Dying is when a terminally ill person in the final stages of their illness voluntarily self-administers lethal medication, usually in the form of a drink that is legally prescribed, in order to end their suffering. Voluntary Euthanasia is when a doctor legally administers the dose – sometimes via a cannula – at the dying person's request.

If we have good palliative care, why do we need VAD?

Australia has one of the best palliative care systems in the world. However, it is a fact that it cannot help everyone. In Palliative Care Australia's own words: "Even with optimal care, not all pain and suffering can be relieved".

Palliative Care Australia estimates the number of people beyond their help at about 4%. Others, including palliative care specialists, put that number at between 5% and 10%. The suffering of these patients and their families, as recorded in evidence to the parliamentary inquiries, can be savage. This is no criticism. It simply reflects 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. The question is: why should those whom palliative care can't help be left to suffer when we have the means to help them?

Voluntary Assisted Dying is not intended to replace palliative care. It adds one more end-of-life option alongside palliative care for doctors and their patients to explore.

What will happen to palliative care once a VAD law is passed?

The good news is that palliative care benefits from Voluntary Assisted Dying laws.

In an October 2018 report on the international experience of assisted dying laws and palliative care, Palliative Care Australia found:

"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".

In countries such as Canada, Belgium and the Netherlands, and in the US states of Oregon and Washington, funding to palliative care services dramatically increased, and access to palliative care improved, following the introduction of assisted dying laws.

In Oregon and Washington State, the vast majority (90%) of people seeking assisted dying were also in hospice (palliative) care.

What are the conditions for accessing Voluntary Assisted Dying in Victoria?

The Victorian law, which was passed in late 2017 and came into effect in June 2019, has been described as the most conservative of its type in the world. It mandates that people can only access Voluntary Assisted Dying if they have a terminal illness that is:

- likely to cause their death within six months (or within 12 months for neurodegenerative diseases like motor neurone disease); and
- causing the person suffering that is unacceptable to them. They must have the ability to make and communicate a decision about Voluntary Assisted Dying throughout a formal three-part request process. They must also:
- be an adult 18 years or over;
- have been living in Victoria for at least 12 months; and
- be an Australian citizen or permanent resident.

What is being implemented in Western Australia?

The WA Voluntary Assisted Dying Act (2019) will come into effect sometime in mid 2021. It closely resembles the Victorian Voluntary Assisted Dying Act (2017), one of the most conservative laws of its kind anywhere in the world. It includes strict eligibility criteria and over 100 safeguards. As in Victoria, access to the process is restricted to adults who have decision-making capacity, who are in the final stages of a terminal illness, who are experiencing suffering that cannot be relieved, and who have repeatedly requested assistance to die.

However, there are several key departures from the Victorian model.

Self-administration of the lethal dose is the preferred method, but unlike in the Victorian regime, a patient could choose for a medical practitioner to administer the drug.

The WA Act also allows a medical practitioner to initiate a conversation with a patient about accessing the voluntary assisted dying option and does not require one of the assessing medical practitioners to be a specialist.

The Act is the result of more than 180 hours of parliamentary debate and extensive consultation with the community and medical, legal and cultural experts. It was informed by recommendations from a Ministerial Expert Panel, which was made up of 13 of the State's leading health professionals, health consumers, and cultural and legal experts.

This process followed the recommendations of a Joint Select Committee on End of Life Choices, which received more than 730 submissions, held 81 hearings and took evidence from more than 130 witnesses over a 12-month period (during 2017/2018). The recommendations are outlined in the report 'My Life, My Choice'.

How will vulnerable groups such as the elderly and people with disabilities be protected?

Despite claims to the contrary, independent and exhaustive reviews from Australia and overseas have shown no credible evidence that VAD laws inevitably expand in scope or lead to the abuse of vulnerable groups (the so-called 'slippery slope'). These reviews include:

- Australian palliative care physician Dr Linda Sheahan, whose 2012 Churchill Fellowship study of overseas jurisdictions concluded: **"The slippery slope in terms of risk to vulnerable groups has not been demonstrated by the data."**
- The cross-party parliamentary inquiries in Victoria and Western Australia, which found: **"no evidence of institutional corrosion or the often cited 'slippery slope'..."**
- The Victorian committee, which concluded: **"Assisted dying is currently provided in robust, transparent, accountable frameworks. The academic literature shows that the risks are guarded against, and that robust frameworks help to prevent abuse."**
- The WA Committee, which confirmed **"There is no evidence to suggest, from either Oregon or the Netherlands data, that people with disabilities are at heightened risk of assisted dying"**.
- The Journal of the American Medical Association in 2016, whose conclusion stated: **"In no jurisdiction was there evidence that vulnerable patients have been receiving euthanasia or physician-assisted suicide at rates higher than those in the general population."**

Perhaps most telling: representatives of peak elderly and disability groups in Belgium, the Netherlands and Oregon also report no abuse of their members under VAD laws.

VAD laws are designed for those at the end stage of a terminal illness whose suffering is beyond meaningful medical help. It is very hard to coerce a vulnerable person into a terminal illness they don't have. Even harder to coerce two doctors, whose work will be subject to review, to agree with them. That's why the safeguards work.

Why do I hear so many negative stories about assisted dying in Belgium and the Netherlands?

Opponents of Voluntary Assisted Dying like to manipulate official figures from Belgium and the Netherlands to paint an untrue picture of proposed assisted dying laws in Australia.

They partially quote from official reports to create an alarming, yet false, impression that there has been a sharp and sustained upward trend in the number of assisted deaths in those countries.

First, and most importantly, the assisted dying laws in Belgium and the Netherlands are fundamentally different from the laws in effect and proposed in Australia.

Unlike the Australian laws, the threshold to access the European laws is weaker – for example people do not have to be suffering from a terminal illness, only experiencing intolerable suffering. This has always been the case under those laws – there has been no expansion over time to weaken this eligibility or include more people.

For this reason, it is wrong to compare the proposed Australian laws with the laws in Belgium and the Netherlands. The European-style laws are not being proposed here and never will be. Australia's laws most closely resemble legislation in the US – it is these laws that we should look to for comparison.

Even so, when all the data from Belgium and the Netherlands are considered, the following becomes clear:

- Euthanasia deaths in Belgium and the Netherlands remain, as they have been since the inception of laws, a tiny percentage of all deaths. In the Netherlands, always around 4 per cent. In Belgium, never above 2 per cent;
- Euthanasia deaths have remained statistically tiny despite an upward trend in total deaths in both countries;
- There was actually a drop in total euthanasia deaths in 2014–15.

Importantly, **the numbers of people accessing assisted dying overseas is extremely low.** It turns out, when people have the option, few take it. Knowing they have a choice and are in control as they die is enough.

Opponents also claim that under the assisted dying laws

in Europe, there has been an increase in the number of people being assisted to die **without their consent**.

This is one of their most mendacious claims. Invariably, the statistics they quote relate to involuntary euthanasia – in other words ‘palliative sedation’ or ‘terminal sedation’ – which takes place even in jurisdictions where there are no assisted dying laws.

People should be aware of this sleight of hand and reject the tactic for what it is – blatant misrepresentation designed to sow fear and confusion.

What do Voluntary Assisted Dying laws mean for the doctor-patient relationship?

According to the AMA’s code of ethics, doctors are obliged to:

Respect the right of a severely and terminally ill patient to receive treatment for pain and suffering, even when such treatment may shorten a patient’s life.

Some doctors object to assisted dying on the basis of the Hippocratic Oath which instructs “do no harm”. Others see **leaving a dying patient to suffer as the opposite of ‘do no harm’**.

The Declaration of Geneva, adopted by the World Medical Association in 1948, is considered an update of the 2400-year-old Hippocratic Oath. It requires medical professionals to consider the **autonomy and dignity** of the patient.

A Voluntary Assisted Dying law is voluntary for everyone. It respects and protects the rights of those doctors who object. Just as it protects and respects the rights of those doctors with a different ethical view.

In countries where assisted dying has existed for up to two decades, research shows **no negative impact on the doctor-patient relationship**; in fact, the exact opposite.

For example, the latest (2017) OECD report on the Netherlands notes that satisfaction with health care is high – 86% – compared to 70% across the OECD. This would hardly be the case if the public had lost confidence in – or were afraid of – the medical profession because of Voluntary Assisted Dying.

This confidence was confirmed by Australian palliative care physician Dr Linda Sheahan in her 2012 Churchill Fellowship report on assisted dying. She found no erosion of trust in doctors where assisted dying/voluntary

euthanasia is legal.

In Australia, too, a majority of doctors who responded to a 2016 survey reported no fears that Voluntary Assisted Dying would damage the doctor-patient relationship – 51.6% agreed that **“euthanasia can form a legitimate part of medical care”**.

In reality, with Voluntary Assisted Dying laws in place doctors do what they already do – make a careful diagnosis that a patient’s condition is terminal and their suffering intolerable and go through with them their treatment options.

If the patient meets the legal requirements for assistance to die, a doctor writes them a prescription for a life-ending medication. After that, it is up to the patient whether or not they use it.

Only one person is being asked to make a life and death decision – the person who is dying.

What does support for Voluntary Assisted Dying say about our attitude to suicide?

Opponents of VAD routinely refer to assisted dying as suicide. This is wrong and dangerous. Voluntary Assisted Dying is NOT suicide. There is NO equivalence.

Suicide is an impulse, acted on in secret, in response to a problem that, with treatment, could most likely be fixed.

Voluntary Assisted Dying is a rational response from an already dying person who simply wants help to avoid the last, most distressing phase of a terminal illness.

This point 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.

This distinction 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’.

Also, there is no credible evidence of increased suicide rates as a result of VAD. The WA Parliamentary Inquiry’s

final report found that “suggestions of suicide contagion are not supported in the evidence”. Moreover, the data in European jurisdictions with assisted dying frameworks indicate that **suicide rates have either remained the same or have fallen**.

While so-called ‘suicide contagion’ as a result of VAD laws is a confection, suicides in Australia for those beyond the help of palliative care are very real.

What about unintended consequences?

The Voluntary Assisted Dying law in place in Victoria, and the one being implemented in Western Australia, are among the safest and most conservative in the world. All unintended consequences have been considered and protected against through strict eligibility criteria and multiple safeguards.

The biggest unintended consequence, however, is one opponents rarely talk about – and it is a result of the *absence* of Voluntary Assisted Dying laws.

Evidence to the Victorian Parliamentary Inquiry from the Coroner’s Office showed that, in the absence of a Voluntary Assisted Dying law and faced with the fear of an agonising death or with unmanageable suffering, terminally ill Victorians were committing suicide at the rate of one a week.

These suicides included asphyxiation by plastic bags and carbon monoxide poisoning, gunshot wounds, overdoses and by hanging. The Victorian coroner even spoke of one 80-year-old man with brain cancer who shot himself repeatedly with a nail gun.

In Western Australia, the Parliamentary Inquiry found 10% of all suicides were by people with terminal or debilitating chronic illnesses who saw no other choice than to take their own life, often violently and alone. In South Australia, SA Police told a parliamentary inquiry that 10% of the suicides in that state were by terminally ill people.

It would be wrong to turn a blind eye to these violent deaths – all unintended consequences of the existing inadequate law – simply because of fears of hypothetical consequences that may never eventuate.

Isn’t there a risk that elderly people will seek assisted dying because they don’t want to be a burden?

Being elderly alone is not a sufficient reason for access to Voluntary Assisted Dying. The person must also be diagnosed with a terminal illness and be approaching death. The reasons why terminally ill people in the final stages of their illnesses choose assisted dying are numerous, and they vary according to the individual. However, the main motivation for seeking assisted dying is to be **in control of the timing of death** and for patients to be able to decide **when they have suffered enough**.

Another important motivation is to spare their family and friends the trauma of having to witness a ‘bad’ death.

There is no evidence from overseas that people choose VAD because they are being coerced or because they don’t want to be a burden on their families.

In Oregon, for example, in surveys of terminally ill people, ‘being a burden’ is not the only – or even the main – motivating factor in their decision. It is just one of the many reasons people list for wanting to choose the time and manner of their death. These include loss of autonomy, loss of dignity, losing control of bodily functions, and fear of unmanageable pain.

In other words, the perfectly rational desire to avoid unnecessary suffering. And a perfectly rational response from terminally ill people to the reality that they are dying.

Australia’s Voluntary Assisted Dying laws are among the safest and most conservative in the world. They explicitly guard against the risk of coercion, requiring a person requesting medical assistance to die to have a diagnosed terminal illness which is expected to cause death within six months (or twelve months for neurodegenerative diseases). They will have to have their application assessed by two independent medical professionals, and state three times their request to die, confirmed by two independent witnesses. Other strict eligibility criteria and safeguards will ensure no one is coerced into using these laws against their will.

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**](http://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 Act 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 that 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. The first practitioner refers the patient to the second practitioner for a consulting assessment. Both doctors must report to the Review Board.

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 SUMMARY ²⁹

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 is 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, as well as 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 is unpredictable - decline can happen swiftly and with devastating consequences even in

those patients whose death was not predicted for many months. Sometimes, too, the suffering of an incurable and irreversible disease is greatest in those who are not immediately dying: rather, they are condemned to even greater suffering over a longer period.

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:

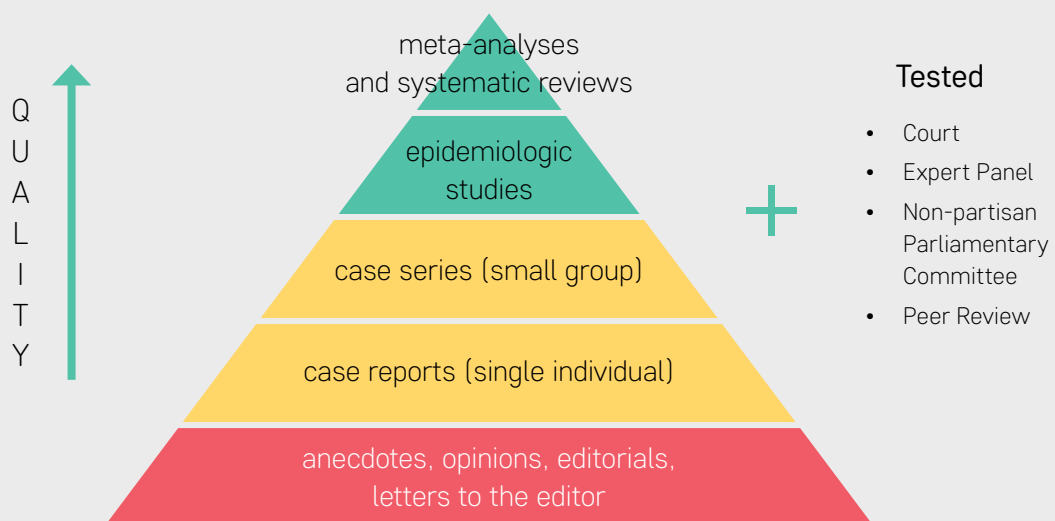
Voluntary assisted dying is a critical social issue. Both sides of the argument have a duty and responsibility to be transparent in their views and also to be clear about the evidence they are relying on. Where there is trustworthy, reliable evidence that sheds light on how voluntary assisted dying regimes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

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.**

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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.