

Guide to the Debate

Restoring Territory Rights

July 2022





Contact

Visit: gogentleaustralia.org.au

Phone: 0468 464 360

Email: contact@gogentleaustralia.org.au

Write to: PO Box Q46, QVB NSW 1230

ABN: 61 613 668 643

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

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

Republished with edits in August 2020, November 2020, July 2021, October 2021 and July 2022.

© Go Gentle Australia 2022

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

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

Guide to the Debate

Restoring Territory Rights

July 2022

"I readily concede that, if there were a state in the Commonwealth which had legislated for euthanasia, I think it would be highly inappropriate for the Commonwealth parliament to say, 'We would not permit the territories to do this...'"

Fr. Frank Brennan, opponent of VAD, speaking to the Senate Standing Committee on Legal and Constitutional Affairs, 2008.



“As each state in turn passes a VAD law, my status becomes even less equal. I chose to become an Australian. I didn’t expect to be a lesser citizen because I live in the NT.”

Judy Dent,
Husband, Bob Dent, was the first person to use the Northern Territory’s voluntary assisted dying law.

Contents

	Introduction	5
Part 1	Why do we need to restore Territory Rights?	6
	It’s wrong for there to be two classes of Australians	6
	Honoring the spirit of self-government	7
	Australia’s landscape has changed since the 1990s	8
	ACT and NT Legislative Assemblies have proved themselves mature and capable	10
	The vast majority of Australians support restoring territory rights	11
	The risks of denying territory rights	12
Part 2	Six questions for federal parliament	14
	Will restoring territory rights fix the democratic inequity?	14
	Will this bill restore the NT’s former law?	15
	Does restoring territory rights compel the NT and ACT to pass VAD laws?	15
	Will restoring territory rights make end-of-life practices more equitable across Australia?	16
	What do Indigenous people think about VAD?	18
	Does allowing self-determination meet community expectations?	20
Part 3	Common questions about VAD	22
	Will facilitating VAD lead to abuse and coercion?	22
	Shouldn’t we just resource palliative care better?	24
	Is it true people are choosing VAD because they feel like a burden?	25
	What is the difference between VAD and suicide?	26
	Is VAD medication reliable?	28
	It’s not just about pain, it’s about suffering	29
Part 4	Why facts matter	30

Introduction

In 1995, the Northern Territory (NT) became the world's first jurisdiction to legislate to allow terminally ill people at the end of life the option to end their suffering by requesting life-ending medication from their doctor.

However, the landmark law was only in operation for nine months before the federal parliament intervened to overturn it in 1997. In that time, only four people were able to access an assisted death.

The law of repeal, the Euthanasia Laws Act (1997), was introduced as a Private Members Bill by Howard Government MP Kevin Andrews. It not only repealed the Rights of the Terminally Ill Act (1995) (NT) but also inserted identical provisions in each of the territories' Self Government Acts to prevent them from debating or passing laws for voluntary assisted dying in the future. Those prohibitions are still in effect today.

The inequity of these prohibitions is emphasised by the fact that, in the past six years, every Australian state has passed its own voluntary assisted dying law. This means almost 700,000 people in the ACT and NT are treated differently from other Australians.

Irrespective of your views on voluntary assisted dying, restoring the territories' right to self-determination on this matter seeks to redress this inequity.

The question before you is not 'do you believe the territories should legalise voluntary assisted dying?' It is: **'Do you believe the territories have the right to decide whether they should legalise voluntary assisted dying?'**

That being said, the two issues are often conflated. For this reason – and to help counter efforts by opponents to block VAD reform – this Guide also contains background information on voluntary assisted dying, why it is a valid end-of-life choice, and how the 'Australian model' of VAD is operating safely and as intended in Victoria and Western Australia.

Ultimately, the debate ahead is about whether Australians living in the NT and ACT can be trusted to make decisions without Commonwealth interference, and whether they should have access to the same legal end-of-life choices as other Australians.

PART 1

Why do we need to restore territory rights?

It's wrong for there to be two classes of Australians

Residents of the NT and ACT should not be treated like second-class citizens in their own country.

It is unjust that almost 700,000 Australians are disenfranchised from the option to legislate on an issue like voluntary assisted dying solely on the grounds of their postcode.

This injustice is thrown into sharp focus by the fact that every state has now chosen to pass voluntary assisted dying laws, while the territories remain hobbled by a 25-year-old ban. Even opponents of voluntary assisted dying acknowledge this inequity.

“I readily concede that, if there were a state in the Commonwealth which had legislated for euthanasia, I think it would be highly inappropriate for the Commonwealth parliament to say, ‘We would not permit the territories to do this’”

Fr. Frank Brennan, opponent of VAD, speaking to the Senate Standing Committee on Legal and Constitutional Affairs, 2008.

‘I didn’t expect to be a lesser citizen because I live in the Northern Territory’

Bob and Judy Dent’s story, NT

Bob Dent, a former pilot and carpenter from Darwin, was the first person to use the Northern Territory’s voluntary assisted dying law in 1996 and the first in the world to make use of a law allowing euthanasia..

Bob had prostate cancer. He had lost 25kg and had a recurring hernia and a collapsed lung. The cancer had infiltrated his bone marrow. He needed a catheter and leg-bag to urinate and was on more than 30 tablets a day.

With his doctor and wife Judy by his side, Bob decided it was time to die – but not before writing a letter to all federal politicians:

For months I have been on a roller-coaster of pain made worse by the unwanted side-effects of the drugs.

Morphine causes constipation – laxatives taken work erratically, often resulting in loss of bowel control in the middle of the night. I have to have a rubber sheet on my bed, like a child who is not yet toilet trained.

I can do little for myself, and require 24-hour nursing care.

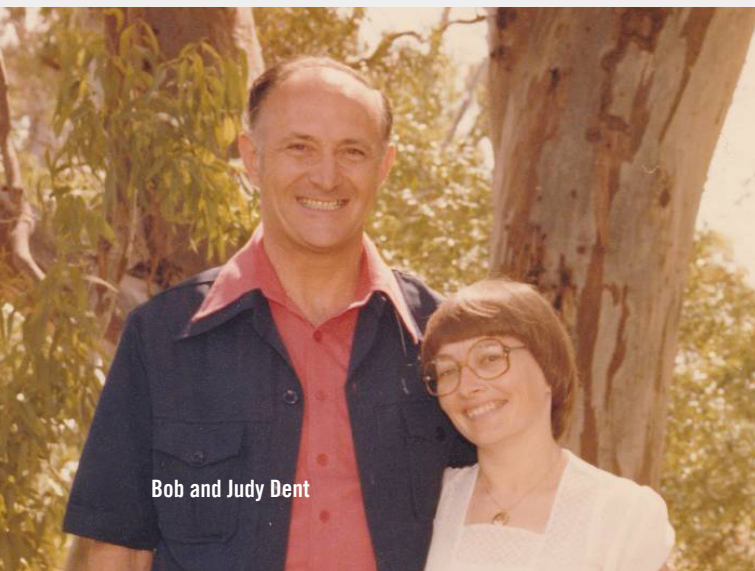
There is now a constant fear of a fall which could cause terrible injury to my fragile bones. I cannot even get a hug in case my ribs crack. If I were to keep a pet animal in the same condition I am in, I would be prosecuted.

If you disagree with voluntary euthanasia, then don’t use it, but don’t deny me the right to use it if and when I want to.

Bob was able to have the autonomy and death he desired – but territorians since have not had the same choices because of the Commonwealth prohibition on the territories even debating assisted dying laws. As these laws have passed in every other state, Bob’s widow Judy and others in the territories have fought to have the NT’s right to self-determination restored.

Judy’s message to federal parliament, 25 years later is clear:

“Get on with it and undo the mistake that you made in 1997. Why must we be treated as second class citizens when it comes to deciding how we die?”



Bob and Judy Dent

Honoring the spirit of self-government

To restrict territories' democratic rights to decide for themselves on voluntary assisted dying laws is an abuse of the intent and spirit of the Self Government Acts and Westminster convention.

The NT and ACT were granted self-government by the Commonwealth Parliament in 1978 and 1988 respectively.

The spirit of this devolution of powers was reflected by the Hon. Clyde Holding MP when introducing the ACT's Self Government Bill:

It will allow 270,000 people the same democratic rights and social responsibilities as their fellow Australians... It ensures that the residents of the Territory will be properly and effectively represented in the management of their affairs. It is a milestone in the democratic processes of this country.¹

Since devolution, the Legislative Assemblies in the NT and ACT have grown into mature and highly effective governments. They have more than proven their ability to legislate responsibly, without Commonwealth interference.

Their populations, too, have grown. Today, for example, the ACT's population of 467,00 is only marginally less than Tasmania's (526,00). Tasmania voted to legalise VAD in 2021.

The authority of the Federal Parliament to override territory law remains unquestioned; however, Westminster convention says such powers are intended to be exercised **only in extreme circumstances such as civil unrest or where the national interest is threatened**. The democratic debate of voluntary assisted dying laws satisfies neither of these thresholds.

There is evidence, too, that continuing to deprive some Australians of their right to have their elected representatives legislate on their behalf may contravene Australia's human rights obligations. This view is supported by ACT Human Rights Commissioner Dr Helen Watchirs, who has said,

In my view, there is a serious question whether the Commonwealth's Euthanasia Laws Act 1997 is compatible with Australia's international human rights obligations.²

1. Clive Holding MP, 2nd reading speech. Self Government Bill 1988 https://www.archives.act.gov.au/_data/assets/pdf_file/0004/562639/Self_Government_Bill_1988_SRS.pdf

2. Dominic Giannini, Commonwealth limiting human rights in ACT over euthanasia position: Minister. The Riot Act, 5 March 2021. <https://the-riotact.com/commonwealth-limiting-human-rights-in-act-over-euthanasia-position-minister/444363>



Australia's landscape has changed since the 1990s

Australia's political and cultural landscape has shifted in the three decades since the Northern Territory's assisted dying law was overturned. Arguments made against the Rights of the Terminally Ill Act in the 1990s are no longer relevant today.

In his submission to the 2008 Senate Legal and Constitutional Affairs Committee Inquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill, the Australian Catholic University's Father Frank Brennan cited the argument he originally made against the ROTI Act back in 1996:

The Commonwealth Parliament may not have the power to overrule a State law legalising the administration of requested lethal injections. It does have the power to overrule a Territory law. Should it ever exercise that power? Only in very rare circumstances; where no State has similarly legislated; where the Territory law is a grave departure from the law in all equivalent countries; where the Territory law impacts on the national social fabric outside the Territory; and where the Territory law has been enacted without sufficient regard for the risks and added burdens for its own vulnerable citizens, especially Aborigines. This is such a circumstance.

In 2022, none of the circumstances cited by Father Brennan as reasons for the Commonwealth to overrule Territory law exist:

- Six Australian states, Victoria (2017), Western Australia (2019), Tasmania, South Australia, Queensland (2021) and NSW (2022) have passed VAD legislation.
- Similar countries in Europe and North America have had such laws for almost quarter of a century as does, now, New Zealand. In total, they are available to over 200 million people worldwide.
- The national fabric of the country is, according to every published poll of the last decade, overwhelmingly supportive of VAD.
- The questions of risks and burdens for vulnerable people have been exhaustively debated in each state parliament that has made VAD legal, with all of those debates launched on the back of extensive public inquiries. It is worth noting that:
 - South Australia's VAD law was introduced and championed by indigenous Australian and shadow Attorney General, Kyam Maher. And one of the first West Australians to use their VAD law was Wongatha-Yamatji woman, Mary-Ellen Passmore.
 - The existence of the Australian laws alone removes any reason to further deny the NT and ACT parliaments the authority to debate and pass voluntary assisted dying legislation should they choose to.
- In 1995, the NT was breaking new ground and leading the world in passing a VAD law. Today, some 25 jurisdictions in 10 countries have passed assisted dying laws, including in all six Australian states. These laws have been shown to be working safely and as intended. The claims by opponents that they would not have proven to be unfounded.

Reform in Australia and New Zealand

Within Australasia, all six Australian states and New Zealand have passed Voluntary Assisted Dying laws.

- Victoria led this change, becoming the first state to enact a VAD law in November 2017. The Victorian Act commenced on 19 June 2019, after an 18-month implementation period
- In December 2019, Western Australia followed suit, passing legislation which commenced operation on 1 July 2021
- In November 2020, New Zealand endorsed an End of Life Choice Act by national referendum, with the law commencing in November 2021



- Tasmania enacted its VAD law in March 2021, followed by South Australia in May and Queensland in September
- NSW became the final state to pass a VAD law in May 2022.

All of Australia's laws follow a similar framework – coined the 'Australian model' of VAD – which limits medical assistance to die to terminally ill adults with decision making capacity who are suffering intolerably. Each law came about after significant levels of public consultation. Each has built on the strengths (and addresses the weaknesses) of laws that came before, both here and overseas.

The result is similar, but not uniform, legislation across the states, based on a considered response to the

unique characteristics and circumstances of each jurisdiction.

More than three years of operation of Victoria's voluntary assisted dying law, and more than 12 months of WA's law, demonstrate that Australia's highly regulated laws are used by a small number of eligible people, and are working safely and as intended. It is now an increasingly mainstream view that medical assistance to die has a rightful place in the spectrum of end-of-life care.

People in the territories do not suffer and die differently from other Australians, and their elected representatives should be able to decide whether these options should be available to their citizens at the end of life.

ACT and NT Legislative Assemblies have proved themselves mature and capable

The ACT and the NT are established democracies that should be free to decide voluntary assisted dying laws in their jurisdictions.

Denying territorians agency on an issue every other Australian legislature has decided for itself is paternalistic and flies in the face of political reality.

Marshall Perron was Chief Minister when the NT's world-first assisted dying legislation passed. Below is an extract from his submission to the Senate Legal and Constitutional Affairs Committee regarding the Ensuring Northern Territory Rights Bill 2021.³

The issue for consideration is whether there is a case for the continued withholding of state powers from the Northern Territory Parliament.

The Northern Territory Parliament and Executive has, for 43 years, responsibly administered a Judiciary (including the appointment of Judges of the Supreme court), a police force, health, education, (including establishing a university) and other services with an annual budget of billions.

It has drawn up a criminal code, legislated for the termination of pregnancy, organ donation, prostitution, aboriginal sacred sites, firearms, and casinos. The NT has, in the past, led the States in developing ties with Indonesia, a no-fault motor accidents compensation scheme, privatising government audit and banking, and digital land titles.

Territorians are no less intelligent, no less educated, no less moral than their counterparts in the states. Their elected representatives can be trusted to carry out their responsibilities in a diligent manner. The qualifications required to stand for election to the Legislative Assembly are the same as any Australian citizen who seeks election to the Senate or the House of Representatives.

The bill being considered here seeks to correct an anomaly in Australia's democracy.



By withdrawing powers that had been transferred to the territories at Self Government, the Federal Parliament effectively divided Australian citizens into two classes on the grounds of geography. The 700,000 who choose to live in the territories (more people than live in Tasmania) cannot elect representatives to legislate on their behalf on end of life issues the way citizens living in the states can.

Disregarding the merits or otherwise of legalising voluntary assisted dying (VAD), the fact that not a single one of the 126 Senators and MHR's who voted for the Euthanasia Laws Bill in 1997 were electorally responsible to Northern Territorians is pertinent. The action may have been constitutional, but it was not democratic.

If there ever was an argument that the Northern Territory Legislative Assembly overstepped the line when it became the first jurisdiction to legalise VAD 26 years ago, it is no longer valid.

3. Marshall Perron. Submission to the Senate Legal and Constitutional Affairs Committee https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/NTRights/Submissions

The vast majority of Australians support restoring territory rights

Australians are strongly in favour of restoring to the territories their right to decide for themselves on voluntary assisted dying laws.

The Australia Institute polled Australians in 2021⁴ and found more than three in four (76%) supported the Commonwealth allowing Territory governments to legalise voluntary assisted dying within their jurisdictions.

The Institute found overwhelming support across all voting intentions.

The think-tank concluded: "There is no reason for either territory to have fewer legislative powers than the states, and that is reflected in the opinion of the Australian people."

	SUPPORT	OPPOSE
COALITION VOTERS	74%	18%
LABOR VOTERS	80%	12%
GREENS VOTERS	77%	15%
ONE NATION VOTERS	73%	14%
OTHER VOTERS	67%	18%

4. The Australia Institute, Polling - Voluntary assisted dying and the territories. April 2021. <https://australiainstitute.org.au/wp-content/uploads/2021/04/Polling-April-2021-Voluntary-assisted-dying-and-the-territories-Web.pdf>



Candles for Compassion Vigil, South Australia 2021

The risks of denying territory rights

There is a real and present urgency to resolving the issue of territory rights and voluntary assisted dying. For as long as the NT and ACT are prohibited from passing VAD laws, dying people will continue to suffer against their wishes, either dying a death they desperately sought to avoid or being forced to take matters into their own hands.

The associated trauma is far reaching. It goes beyond the person who is dying; it affects all those left behind – loved ones, nurses, first responders – who have to pick

up the pieces. The number of these stories in the NT and ACT is a sad indictment on a situation in which terminally ill people are not allowed to decide the circumstances of their own deaths.

Below are the stories of two families whose loved ones were denied VAD choice and who continue to feel the pain of the prohibition on the territories enacting VAD laws.

‘Do we have to leave our homes and go interstate to die?’

The story of Stephen and Ruth Wedd, ACT

Ruth Wedd found herself in an impossible position when her husband Stephen, dying of brain cancer, asked her to help end his life. The couple had been married for 20 years. The 18 months since Stephen's diagnosis had seen him lose almost all his ability to communicate and he was very anxious. Ruth told *The Canberra Times*:

He said, ‘You can do it’... He couldn’t elaborate, but I knew what he meant. He expected me to do something [to end his life].

I thought this is something that a family member should not be asked to do. It’s that balance between knowing it is totally illegal and yet being able to satisfy one of the last wishes of someone that you love. There needs to be a system – families should never have to face that.⁵

Ruth did not carry out Stephen's request – but it has complicated her grief that she was not able to respond to her husband's plea for help or give him the death he wanted.



Ruth and Stephen Wedd

Stephen struggled on for another month before he died. Although Ruth has only positive reports of the care he received, the health teams' efforts were futile in the face of Stephen's suffering.

It crossed my mind at the time [of Stephen's death], and it crosses my mind still – ‘Do we all have to leave our homes and go interstate to die’?

I just think as a civil society, how can we think it is OK that someone starves to death, and more pertinently dehydrates to death, and we don't think it's acceptable that they have some assistance to die in a calm and considered way.

Ruth strongly supports terminally ill people having the option of voluntary assisted dying and was part of *The Canberra Times* Our Right to Decide campaign in 2021.⁶

5. Dan Jervis-Bardy, Ruth Wedd backs ACT's right to make own euthanasia laws. July 31 2021. The Canberra Times. <https://www.canberratimes.com.au/story/7358284/stephen-made-a-heart-wrenching-request-to-his-wife-of-20-years/>

6. ACT euthanasia debate: The Canberra Times launches Our Right to Decide campaign, July 27 2021. The Canberra Times. <https://www.canberratimes.com.au/story/7348126/our-right-to-decide-the-acts-right-to-make-its-own-euthanasia-laws/?cs=14260>

'I wanted to be there with her'

The story of Sharon Cramp-Oliver and her mum Liz, NT

Sharon Cramp-Oliver's mother Liz Holmes ended her own life in 2017, aged 77, after developing terminal breast cancer. She was adamant she wanted a choice at the end of life and, when her suffering became unbearable, ultimately opted to end it, desperate and alone.

Sharon says her mother, who lived in NSW, had spoken numerous times about her wish to end her life on her own terms. "She was very determined and very courageous".

Mum was like my best friend. She was an incredible mother and a beautiful soul. I wanted to be there with her but she was adamant she didn't want me to see her in the state she was in and she didn't want me or anyone else to be implicated in her death.

Sharon is devastated she was not able to be there for her mother when she needed her most. Since her mum's death, Sharon has written to all members of parliament, both in the NT and federally, on numerous occasions, and also separately to Prime Minister Malcolm Turnbull (October 2017), NT Chief Minister Michael Gunner (April 2018) and even the Queen and the Governor-General (May 2018). All correspondence contained a plea to allow all Australians, including those in the NT, the right to pass voluntary assisted dying laws. In the correspondence were extracts from her mother's final letter.



Dear Madam / Sir,

My Mum (Elizabeth Anne Holmes) broke her back when she was 53, she battled breast cancer for 12 years, and had 2 hip replacements (one that dislocated itself early in 2017).

She had a terrific career; she worked in a bank, she raised money in the Miss Australia Quest, worked as a model, worked in retail, worked as a divisional secretary for a prominent insurance company, and also worked as a volunteer Lifeline counsellor for 18 years.

And most importantly, Mum was a devoted and dedicated wife and mother.

Mum kept a very detailed diary which explains in detail the decisions she was faced with before she took her own life on September 22nd, 2017. Mum was 77 years old when she died. (Her diary was tabled in the NT Parliament on November 23rd, 2017).

The day Mum died, a letter was found on her dining table:

"To everyone I love, especially Wayne, Sharon and Wendy.

I was so looking forward to my life after my two hip surgeries. I have not been able to walk or drive for years.....Now I cannot even walk [my dog] Katie!

'I thought okay, if I cannot walk, I will swim and I cannot do that as well. My grade four breast cancer has progressed and has broken through the skin...

I have had 24 years of pain. I am not going to burden my children and friends and have palliative care. What a farce that is! Because there is no option in New South Wales, I choose euthanasia...

I watch TV, I read, I do crosswords. I have become a hermit, with a dog called Katie, my saviour. I have nothing to look forward to but pain and indignity. We all should be able to choose when we die, so with great courage and no cowardice I go to God. An act of love. Please cremate Katie so she can be with me.

Love, Mum."

As an Australian citizen, ALL Australians should have the same rights; no matter whether you live, whether it be in a State or a Territory. Please take action and support the Northern Territory.

Thank you, Sharon Cramp-Oliver

PART 2

Six questions for federal parliament

Will restoring territory rights fix a democratic inequity?

Now that every Australian state has passed a voluntary assisted dying law, a legislative asymmetry has emerged between the states and territories; residents of the NT and ACT are disenfranchised from deciding on an important aspect of their life and death. This bill will restore to the territories self-determination on the issue of assisted dying.

Of course, the federal parliament retains its constitutional authority to override territory laws.

However, this bill honours the Westminster convention that devolved powers would only be repealed in extreme circumstances, such as civil unrest or where the national interest is threatened. With end of life choice now approaching mainstream acceptance in Australia, this threshold is clearly not reached with regard to assisted dying laws. Federal Parliament must now restore to the NT and ACT the power to debate and pass such laws.



Will this bill restore the NT's former VAD law?

The original Rights of the Terminally Ill Act (1995) was repealed by the Euthanasia Laws Act (1997). The NT's Legislative Assembly would need to pass new legislation in order to once again legalise voluntary assisted dying.

Although the Northern Territory legislation is still on the statute books, NT Attorney-General Chansey Paech has said there are no plans to simply reinstate the 1995 Act. Any NT VAD law would need to be re-written and modernised.

Mr Paech recently told the ABC: "We are working on contemporising that legislation to make sure that it's in line. Best practice standards have changed a lot since [1995]."

The bill before the federal parliament, if passed, would simply repeal:

- Provisions in the self-government Acts of the NT and ACT that preclude their respective legislative assemblies from making laws relating to VAD
- The Euthanasia Laws Act 1997 in its entirety.

Does restoring territory rights compel the NT and ACT to pass VAD laws?

If the bill were to pass federal parliament, it would not automatically legalise voluntary assisted dying in the territories – those legislatures would then need to pass their own legislation.

Whether such laws are right for these jurisdictions, and what form they will take, is a matter for the territories; indeed, this autonomy to make their own policy and laws is exactly what the federal territories rights bill seeks to achieve.

“Territorians know what is best for the territories... Territorians deserve to have a say on how these law can affect them.”

Northern Territory Chief Minister, Natasha Fyles

Will restoring territory rights make end-of-life practices more equitable across Australia?

By December 2023, every state will have an operational voluntary assisted dying law.

This creates inequity not just between people living in states compared to those in territories, but between individual territorians. People in the NT and ACT who:

- live on the Queensland and NSW borders
- are former residents of Queensland or NSW, or who have strong family ties in those states
- have the means to move interstate
- have the means to travel abroad to countries such as Switzerland

... can access an assisted death. (In the cases of those living on the borders of NSW and Queensland, those states' laws allow exemptions to their residency requirements based on compassionate grounds and/or medical service provision).

For people in the NT and ACT to whom the above does not apply, the options available are few, often dire, and involve inconsistencies.

There will always be a small number of people who are able to access an assisted death, even if unlawful. Those people generally possess some privilege; contacts and connections in the medical or veterinary professions, for example. As one critique 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.⁷

For all who live in the NT and ACT, the opportunity to allow their parliaments to at least debate this issue will be a first and important step to addressing this inequality.

A postcode lottery for voluntary assisted dying access

Continuing to deny the territories self-determination on voluntary assisted dying ensures that Australians have unequal rights at the end of life, adding to the pain and suffering experienced. The circumstances that Sue Walton and her stepdaughter Katie found themselves in illustrates the terrible choices territorians will increasingly face should territory rights be denied.

The story of Sue Walton and her stepdaughter Katie

Sue Walton's stepdaughter Katie was diagnosed with stage 4 cancer in July 2021, aged 35, and given three months to live. Two weeks' earlier, she had given birth to a baby boy.

As an aged care worker, Katie was more familiar with the end of life than most. She told Sue that she'd applied for voluntary assisted dying in Victoria, where she had recently moved. Voluntary assisted dying laws had been effective in Victoria for almost two years at that time.

However, Sue and the rest of Katie's family lived in NSW. Although Katie longed to return to them to share the final months of her life, doing so would mean she could not legally access an assisted death; voluntary assisted dying was still illegal in NSW at the time.

⁷ Ronald Dworkin et al, The Philosophers' Brief 1997 to the US Supreme Court, quoted in A Good Death: An Argument for Voluntary Euthanasia by Rodney Syme, 2008, Melbourne University Press

Despite undergoing a rigorous assessment process and now having a locked box of life-ending medication in her possession, Katie would be breaking the law if she ended her life at home with her family in NSW.

The final months were complicated for the family, with long drives back and forth to Melbourne for Sue. Flying was out of the question, as Sue's husband had a compromised immune system. They had to negotiate each state's pandemic restrictions to be able to support Katie and help care for their new grandson, Jameson.

The family's last time together was Christmas in NSW. Sue told *Guardian Australia*:

If the law was in NSW, she would've been here with us and all her sisters, all her friends and all her family... But with all our hearts broken she went back to Victoria.

Sue had promised to be at Katie's side when she took the medication – but a sudden deterioration in Katie's health after her son turned seven months' old meant that Sue did not make it to Melbourne in time. Katie was losing

consciousness and with little time left opted to take the medication. She died with her husband by her side, but not her stepmother or father. Sue told *Guardian Australia*:

I don't make a promise easily... And I now have to live with the fact that I didn't keep my promise to be there for Katie's last breath. And I don't know whether she would've known or not, but I know myself. So that's just another thing that breaks my heart.

“It was an extremely emotional time... she dearly wanted to stay at home and be with us all for whatever time was left. But with all our hearts broken, she went back to Victoria.”

Sue Walton



Photos: Guardian Australia. Image left: Sue Walton.
Image right: Sue holds a photo of herself and stepdaughter Katie.

What do Indigenous people think about VAD?

Some Indigenous leaders have expressed mistrust of voluntary assisted dying laws, particularly in light of poor health outcomes for Aboriginal Australians over many years.

Yet the answer to this is not to block debate about voluntary assisted dying. As we do with other substantive issues, the answer is to allow debate so that everyone can engage on the issue and have their voice heard.

There is much to recommend a thorough consultation process ahead of any debate on voluntary assisted dying legislation, as has been undertaken in every Australian state on this issue. This should include consultation with Indigenous Australians.

We would however caution against assumptions that Indigenous people speak with a single voice on VAD. Like other segments of our population, a variety of views exist.

In the Northern Territory, three of the four federal parliamentarians are Indigenous. Among them, Malarndirry McCarthy and Marion Scrymgour are firm supporters of both territory rights and voluntary assisted dying laws. The third, Jacinta Nampijinpa Price, supports territory rights in principle but opposes assisted dying.

Among the NT's six Indigenous MLAs there are a range of views on assisted dying. All, however, support territory rights.

In South Australia in 2020/21, then Shadow Attorney General and Aboriginal Affairs spokesperson Kyam Maher (now Attorney General) was responsible for

drafting and championing the Voluntary Assisted Dying Bill 2020. He introduced his bill in the state's Legislative Council, sharing his experience of his mother's death to pancreatic cancer:

My Mum Viv... She was a proud, fierce, strong woman, an advocate and fighter for older women, marginalised people and for her Aboriginal community... She ran the women's shelter in Mount Gambier, worked as a social worker at Centrelink and dedicated her final working years to Pangula Mannamurna, the Aboriginal Health Service in Mount Gambier. For her work and dedication she was awarded life membership to the Labor Party, life membership of the Australian Association of Social Workers and awarded the South-East's NAIDOC Lifetime Achievement Award for service to her Aboriginal community...

Viv lived her life with great dignity, and she ought to have had the right to choose to die with the same dignity.⁸

In Queensland, all three MPs who identified as Aboriginal or Torres Strait Islander strongly supported the state's Voluntary Assisted Dying legislation.

In Western Australia, the first identified person to use the state's Voluntary Assisted Dying law in July 2021 was Wongatha-Yamatji woman Mary-Ellen Passmore (see opposite page).

8. Kyam Maher MLC, second reading speech in the SA Legislative Council, 2nd Dec 2020, p5 https://d3n8a8pro7vhmx.cloudfront.net/saves/pages/46/attachments/original/1611041599/Maher_2nd_Reading_VAD_Bill.pdf?1611041599



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

'Eternally thankful' – Mary-Ellen Passmore

In July 2021, a 63-year-old Indigenous woman from Perth became the first identified Western Australian to use the state's Voluntary Assisted Dying law. Her story was told to *Go Gentle* by her family. It was also published in *The West Australian*⁹ and SBS¹⁰.

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

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

"All were singing along to 'Hallelujah', including her doctors," her sister said.

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

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

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

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

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

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

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

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

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

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

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

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

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

Does allowing self-determination meet community expectations?

Beyond the issue of territory rights, Australians – including those living in the NT and ACT – 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 shows support for voluntary assisted dying to be above 70%.

In the most recent polls, support has remained stable at between 75% and 88%, according to Newspoll (2012)¹¹, The Roy Morgan Snap Poll (2017¹²), The West Australian (2018¹³ and 2019¹⁴), ABC's VoteCompass (2019)¹⁵ and The Australia Institute (2021)¹⁶.

The 2019 VoteCompass data for the territories revealed:

- ACT: 80% agreement with voluntary assisted dying and 9% disagreement. (25,000 respondents across five electorates).
- NT: 79% in favour, and 9% disagreement (over 4,500 respondents)

Support is strongest among National Seniors. In a 2021 survey of over 3,500 seniors nationwide¹⁷, a strong majority, 85.71%, strongly agreed or agreed with making voluntary assisted dying provisions available to eligible people who have a terminal illness. This included 86.2% of respondents in the NT and 87.4% in the ACT.

89%

**of Australian voters
now support voluntary
assisted dying**

A jump of 15 percentage points in 6 years¹⁸

Support for VAD and self-determination across the medical professions

A significant number of doctors, nurses and allied health professionals support voluntary assisted dying, recognising this choice as a key part of person-centred care. This support is echoed by professional bodies, the majority of whom are either supportive or believe it is a matter for governments and society to decide.

The Royal Australian College of General Practitioners, the Royal Australasian College of Physicians, the Australian and New Zealand College of Anaesthetists, the Australian Medical Students Association, Palliative Care Australia, and the Australian Nursing and

11. Newspoll, 2012 https://cdn.theconversation.com/static_files/files/6/76079-2017-04-24-polling-121104_Dying_with_Dignity_Report_Revised.pdf?1518043821

12. Roy Morgan snap poll, 2017 <http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349>

13. West Australian, 2018 <https://thewest.com.au/news/wa/assisted-dying-debate-poll-reveals-huge-support-for-voluntary-euthanasia-laws-ng-b881020998z>

14. West Australian, 2019 <https://thewest.com.au/news/health/voluntary-assisted-dying-nine-out-of-10-west-australians-want-euthanasia-laws-according-to-poll-ng-b881302205z>

15. Catherine Hanrahan, 'Euthanasia support strengthens to nearly 90pc, Vote Compass data shows', ABC, May 9 2019 <https://www.abc.net.au/news/2019-05-08/vote-compass-social-issues-euthanasia-transgender-republic-drugs/11087008>, VoteCompass, 2019 <https://www.dyingforchoice.com/VoteCompass2019/>

16. 'Polling: NSW Voluntary Assisted Dying' 19 July 2021 <https://australiainstitute.org.au/report/17300/>

17. <https://nationalseniors.com.au/uploads/VAD-Report-correct-month-12.8.21.pdf>

18. ABC Vote Compass, 2019 <https://www.abc.net.au/news/2019-05-08/vote-compass-social-issues-euthanasia-transgender-republic-drugs/11087008>



Midwifery Federation, have all either backed a voluntary assisted dying law or confirmed that it is a matter for governments and society.

One of the few medical organisations to still oppose voluntary assisted dying, the Australian Medical Association (AMA), is also shifting its stance. While the national body remains opposed, several state-based chapters of the AMA have moved their official positions to 'neutral' and according to a 2016 survey conducted nationally¹⁹, a majority of AMA members (51.6%) agreed assisted dying "can have a legitimate role in modern medical care".

“Working as a VAD physician has enabled me to give back to the community using my medical qualifications in a way that I did not anticipate.”

Dr James Hurley, general diseases physician, Victoria

19. Review of AMA Policy on Euthanasia and Physician Assisted Suicide – Member Consultation Report, December 2016. <https://www.ama.com.au/articles/review-ama-policy-euthanasia-and-physician-assisted-suicide-member-consultation-report>

PART 3

Common questions about VAD

As parliamentarians, you are likely to hear many unsubstantiated claims, hypotheticals and downright misinformation about voluntary assisted dying. Below are answers to some of the most common questions about VAD.

Will facilitating VAD laws lead to abuse and coercion?

Some opponents suggest that family members or carers could pressure or 'steer' an elderly person to request assistance to die in order to, for instance, access an inheritance sooner. They point to concerning levels of elder abuse that exist in our community, exposed by Australia's Royal Commission into Aged Care Quality and Safety.²⁰

Elder abuse is a serious problem. It is only made possible by abusers acting in what they believe to be secrecy. A VAD law makes such abuse less likely by bringing practices that are currently happening in secrecy into the light. Parliamentary inquiries into end-of-life choices in Australia have found that some doctors do, currently, assist people to die, but that they do so 'without support, without transparency or accountability'.²¹ VAD law encourages better practice. It brings regulation and scrutiny to a space that is currently unregulated. It specifically insists that doctors examine questions of competency and coercion. And it offers the vulnerable protections they currently do not have, with strict eligibility criteria and strong safeguards which apply only to those for whom the law is written.

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

There is far more involved in accessing assisted dying than merely a patient requesting it.

The opinion of medical professionals that the person's condition meets strict criteria is required. Failure by doctors to follow the rules means they risk losing their licence or going to jail. Research in jurisdictions where voluntary assisted dying is legal, including in Victoria, demonstrates no evidence of elder abuse as a result of these laws. Victoria's VAD Review Board applies forensic oversight to every stage of the VAD application process. It says:

*The Voluntary Assisted Dying Act 2017... is interpreted in a very strict way, and the Board continues to have a very low threshold for errors or inconsistencies in applications in order to maintain public safety.*²²

Since Victoria's legislation was implemented, compliance has been extraordinarily high. Of the 597 cases in the first two years where people were issued VAD permits, there have only been eight reports of noncompliance. None were related to eligibility of the applicant, or to the quality of clinical care. There have been no referrals to police or the coroner for further investigation.²³

By contrast, other existing end-of-life practices – terminal sedation, and voluntary refusal of food and

20. Royal Commission into Aged Care Quality and Safety Final Report – Care, Dignity and Respect: Volume 2, page 94 – https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-2_0.pdf

21. Parliament of Victoria, Inquiry into end of life choices – Final Report, June 2017, p. 207 https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

22. Voluntary Assisted Dying Review Board, Report of Operations July-December 2020, Safer Care Victoria, p. 14, https://www.bettersafecare.vic.gov.au/sites/default/files/2021-02/VADRB_Report%20of%20Operations%20Feb%2021_FINAL.pdf

23. Voluntary Assisted Dying Review Board, Reports of Operations, Safer Care Victoria <https://www.bettersafecare.vic.gov.au/reports-and-publications?f%5B0%5D=agency%3A751&search=voluntary+assisted+dying+review+board&>

fluids – involve little, or no, regulation, or oversight. There is no central record of their use and no requirement for doctors to examine capacity of the person or the potential that their decision to hasten death may be as a result of coercion.

Sadly, there will always be those who seek to abuse others. VAD law has been built – and has been shown – to protect against this.

It would be far easier for a malicious individual to encourage an elderly relative to overdose on their everyday medication, for example, than it would be to risk the many levels of scrutiny required of the VAD assessment process.

WA's Ministerial Expert Panel found:

... Where voluntary assisted dying is practised, systematic reviews have found that coercion is rare... In fact: Anecdotal reports suggest that coercion from relatives is more likely to take the form of an attempt to dissuade the person from voluntary assisted dying.²⁴

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

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

It is **abuse** to force vulnerable people to suffer a painful and drawn-out death against their wishes. It is **coercion** to leave a dying person the choice of only further treatment (which has become intolerable) or suicide.

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

24. A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018, – <https://www2.health.wa.gov.au/media/Files/Corporate/Reports-and-publications/End-of-life/End-of-Life-My-Life.pdf>



"Dad didn't choose death. Dad chose life over and over again. He chose it when he knew he would have his insides ripped out. He chose it when he knew he would have chemotherapy that would make him sick for another six months. He chose life, he chose life, he chose life. And when life was no longer a choice, he decided to die on his own terms."

Katie Harley

Father, Phil 70, metastatic bowel cancer, chose VAD, Victoria, October 2019



Scan or click the QR code to hear more of Katie and Phil's story in **Better Off Dead Season 2, Ep 8, 'Lucky Phil.'**

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 as they die.

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

Regardless of resources, there are clear limits to the effectiveness of palliative care.

There are also patients with chronic and progressive illnesses – such as advanced Multiple Sclerosis or motor neurone disease – who, because of the long term nature of their suffering, do not easily sit within the palliative care system. As well, some patients do not wish to die a 'medicalised' death, even one in palliative care. According to the Grattan Institute, 70% of Australians wish to die at home but only 14% do.²⁵ 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 everyone strongly supports 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.

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

*There is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards ... if anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.*²⁶

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

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

\$1 Billion

The additional funding allocated to Palliative Care since 2017 as a result of the passage of VAD laws*.

*Based on public announcements by state governments.

That palliative care and VAD go together is borne out by Victoria's most recent Voluntary Assisted Dying Review Board report. It showed that more than 80% of terminally ill Victorians who chose a doctor's help to die were also receiving palliative care.

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

VAD 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.

²⁵ Hal Swerisson and Stephen Duckett, Dying Well The Grattan Institute, September 2014 <https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>

²⁶ Aspex Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector – Final Report 28", Palliative Care Australia, October, 2018,

Is it true people choose VAD because they feel a burden?

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

No one in Oregon chose an assisted death because they feared 'being a burden'

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

When Oregon data is examined in context,²⁷ being a burden is not the only – or even the main – motivating factor for choosing assistance to die. In fact, it is well down the list, the chief reasons being loss of autonomy, dignity and enjoyment in life.

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

The diseases they are dying of – mostly cancer, but also congestive heart failure and neurological diseases such as motor neurone disease – can all be seen on the yearly reports published by the Oregon Department of Health.²⁸

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

CHARACTERISTICS	2020		TOTAL	
	(N=245)		(N=1,905)	
END OF LIFE CONCERNS				
LESS ABLE TO ENGAGE IN ACTIVITIES MAKING LIFE ENJOYABLE (%)	231	(94.3)	1,713	(89.9)
LOSING AUTONOMY (%)	228	(93.1)	1,725	(90.6)
LOSS OF DIGNITY (%)	176	(71.8)	1,308	(73.6)
BURDEN ON FAMILY, FRIENDS/CAREGIVERS (%)	130	(53.1)	905	(47.5)
LOSING CONTROL OF BODILY FUNCTIONS (%)	92	(37.6)	822	(43.1)
INADEQUATE PAIN CONTROL, OR CONCERN ABOUT IT (%)	80	(32.7)	522	(27.4)
FINANCIAL IMPLICATIONS OF TREATMENT (%)	15	(6.1)	86	(4.5)

SOURCE: OREGON DEATH WITH DIGNITY ACT, 2020 DATA SUMMARY

27. Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: 2020 Data Summary", Oregon Public Health Authority, July 15 2020, p.7 – <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf>

28. Death with Dignity Act Report – 2018 – <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2018.pdf>

What is the difference between VAD and suicide?

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

Faced with a terrible choice – a slow, agonising death by fire, or a quick death by jumping – many New Yorkers chose to jump. Seeing this as a rational choice to avoid needless suffering, Hirsch refused to classify their deaths as 'suicides'.²⁹

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.*³⁰

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

*Health practitioners who follow an exacting process to assist a dying person to choose the timing of their death should not be characterised as assisting suicide.*³¹

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

*Words can cause harm. Any linkage between euthanasia and suicide has the potential to cause harm. We recommend that any public debate surrounding euthanasia refrains from making the link to suicide, as this can provoke suicidal ideation.*³²

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

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

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

During WA's parliamentary inquiry, the State Coroner presented evidence that one in ten suicides in WA in any year are by people suffering with terminal or debilitating chronic diseases.³³

Prior to the introduction of Victoria's VAD law, State Coroner John Olle estimated a similar number of

29. Vickers, Matt, *Lucretia's Choice: A Story of Love, Death and the Law*, Text Publishing, 29 August, 2016, p. 231 – <http://tinyurl.com/y36mt867>

30. A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices", p. xxxviii, 40th Parliament, Parliament of Western Australia, August, 2018, – <https://www2.health.wa.gov.au/~media/Files/Corporate/Reports-and-publications/End-of-life/End-of-Life-My-Life.pdf>

31. Queensland Law Reform Commission, Report 79: A legal framework for voluntary assisted dying, May 2021, p. 8 – https://www.qirc.qld.gov.au/_data/assets/pdf_file/0020/681131/qirc-report-79-a-legal-framework-for-voluntary-assisted-dying.pdf

32. "Lifeline Position Statement on Euthanasia, 2013". Email to Go Gentle Australia, Lifeline WA, 10 July 2019

33. A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018 – <https://www2.health.wa.gov.au/~media/Files/Corporate/Reports-and-publications/End-of-life/End-of-Life-My-Life.pdf>

suicides each year – around 10% – were by people with chronic, debilitating or terminal illnesses. When asked if palliative care and support services might have reduced these 240 suicides between 2009-13, he responded:

*The people we are talking about ... have made an absolute clear decision. They are determined. The only assistance that could be offered is to meet their wishes, not to prolong their life.*³⁴

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

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

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

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

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

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

As the WA Parliamentary Committee said:

*It is impossible to quantify the number of people who attempt suicide and fail. However, there is evidence that many do and are left further debilitated.*³⁵

Providing terminally ill people, who are suffering without relief, a safe, reliable way to end their suffering through VAD offers them a better choice than ending their lives prematurely, while they still have the physical capability, or risking a botched attempt that leaves them in a worse state than before.

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



Margaret Hogg accessed VAD in Victoria in 2020. VAD allowed Margaret to say goodbye surrounded by her family and bathed in love – a stark contrast to the violent and lonely death she had contemplated.



Scan or click the QR code to hear Margaret's daughter Lisa explain why offering a dying person a choice about how they die has nothing to do with suicide, in *Better Off Dead* Season 2, Ep 2, 'The Fire & the Fall.'

³⁴. Coroner John Olle, Coroner, Coroners Court of Victoria, Transcript of evidence, 7 October 2015, p. 9 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI_-_Coroners_Court_-_FINAL_-_End-of-life_choices_7_October_2015.pdf

³⁵. A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices, p. xxxviii, 40th Parliament, Parliament of Western Australia, August, 2018, – <https://www2.health.wa.gov.au/~media/Files/Corporate/Reports-and-publications/End-of-life/End-of-Life-My-Life.pdf>

Is VAD medication reliable?

VAD medication in Australia is extraordinarily safe and reliable.

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

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

As one of Australia's leading experts in clinical pharmacology, Professor Dooley has an extensive background in oncology and palliative care and runs a research centre into medicine safety at Monash

University. He says the VAD system is working as intended:

There is a rigorous protocol. It tells you exactly what medication can be used, both orally and intravenously, gleaned from research and overseas experience. Of all the patients that we've treated to date, there haven't been any... that have taken the medication and not passed away.

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

The most common words he has heard used by families to describe their loved ones' deaths were "beautiful", "peaceful" and "dignified".

Professor Dooley told ABC RN in May 2022:

To date we've treated and supported hundreds of patients through this process and it's been shown to be safe and working well for the patients and their families...the Victorian process is robust.³⁶

36. RN Life Matters. Talkback — voluntary assisted dying laws passed in all state. May 30 2022. ABC RN. <https://www.abc.net.au/radionational/programs/lifematters/voluntary-assisted-dying-laws/13901552>



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

**Professor Michael Dooley,
Victorian Statewide Pharmacist**



Scan or click the QR code to hear more from Professor Michael Dooley on the safety of VAD medication, in Better Off Dead Season 2, Ep 6, 'The Locked Box.'

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

Suffering is an intensely personal experience and is not confined to physical pain. People suffering life-limiting illnesses experience symptoms that are challenging to assess, treat and manage – even with the best palliative care. This is widely acknowledged, including by Palliative Care Australia³⁷ and the Australian Medical Association.³⁸

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

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

This range of symptoms is indicative, not exhaustive, and reveals that suffering is not confined to the final stage of a terminal illness.

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

- Two doctors also have to agree that what you say is intolerable suffering matches their reasonable expectation, based on your medical history and symptoms.
- Since you must have a terminal disease to access VAD, it is highly likely that the first doctor you consult has already been treating you for that disease, knows your medical history and disease's trajectory, and is well-placed to consider a claim of intolerable suffering.

- Any doctor who receives a request for VAD, even if they have not been treating you, will consult your medical records. Proof is needed – because all records of a lawfully approved VAD request will go to the VAD Review Board for examination.
- Both independent doctors are also required to discuss all treatment options with you, to see if there are other ways to address your suffering which may be more effective, or have not been explored.

³⁷. Palliative Care Australia, "Policy statement on voluntary euthanasia", Canberra, 2006, p.2. Quoted by: Neil Francis, "AMA uncovered: How its own review exposed its assisted dying policy as indefensible", Dying for Choice, 27 March, 2017, p.20 – <http://www.dyingforchoice.com/docs/AMAUncoveredFullReport27Mar2017.pdf>

³⁸. Australian Medical Association, "Review of AMA Policy on Euthanasia and Physician Assisted Suicide – Member Consultation Report", 2016.



"He didn't want motor neurone disease to win... it had done enough damage to him and he knew what the outcome would be."

Jean & Michelle Caliste whose son Robbie accessed VAD in Victoria in 2019



Scan or click the QR code to hear the Caliste family explain the difference between pain and suffering, in *Better Off Dead* Season 2, Ep 1, 'The Belly of the Beast.'

PART 4

Why facts matter

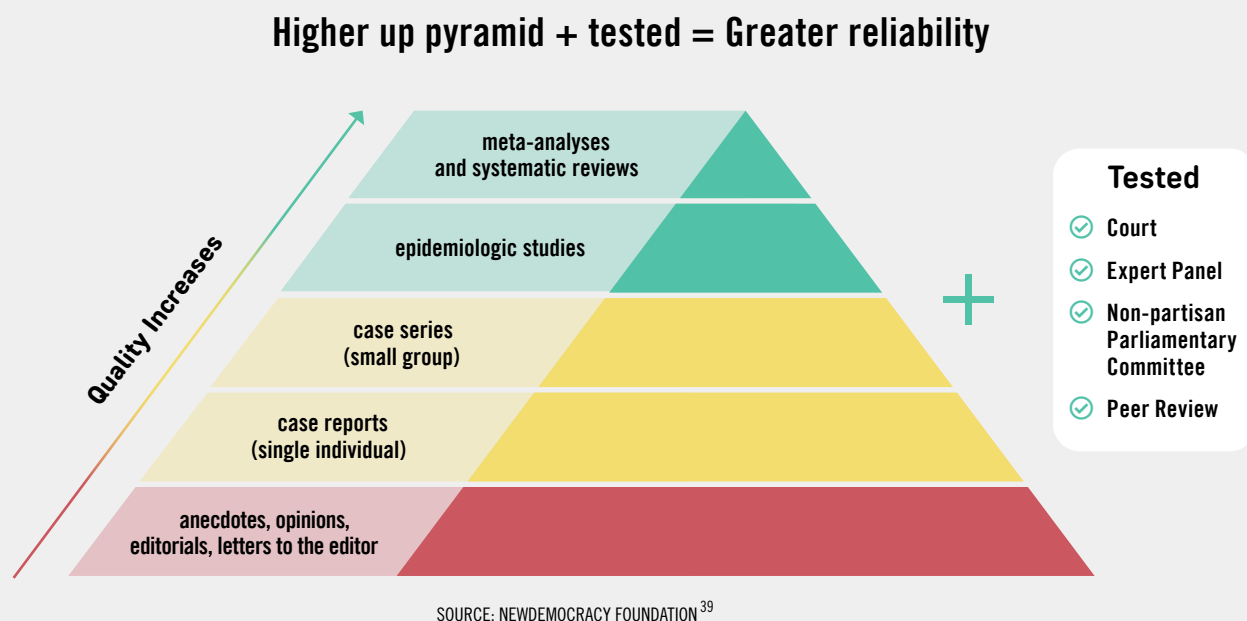
Ben White, Professor in the Australian Centre for Health Law Research at QUT, an independent researcher who has been working in this field for 18 years, has this to say about the importance of relying only on substantiated evidence in debates about important social policy issues, including voluntary assisted dying.

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

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

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

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



³⁹ Ben White, Andrew McGee and Lindy Willmott, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", The Conversation, 20 September, 2017 – <https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195>

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

- Look carefully at the evidence at the top of the evidence pyramid;
- Keep in mind the vast experience of the clinicians and others, who have informed the writing of these laws;
- Remember for whom VAD laws are intended – those who are dying and suffering, and who are seeking a choice about how much they need to suffer;
- Evaluate VAD laws and processes as a whole and resist picking out individual provisions in isolation.

“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.”⁴⁰

Ben White, Professor in the Australian Centre for Health Law Research at Queensland University of Technology

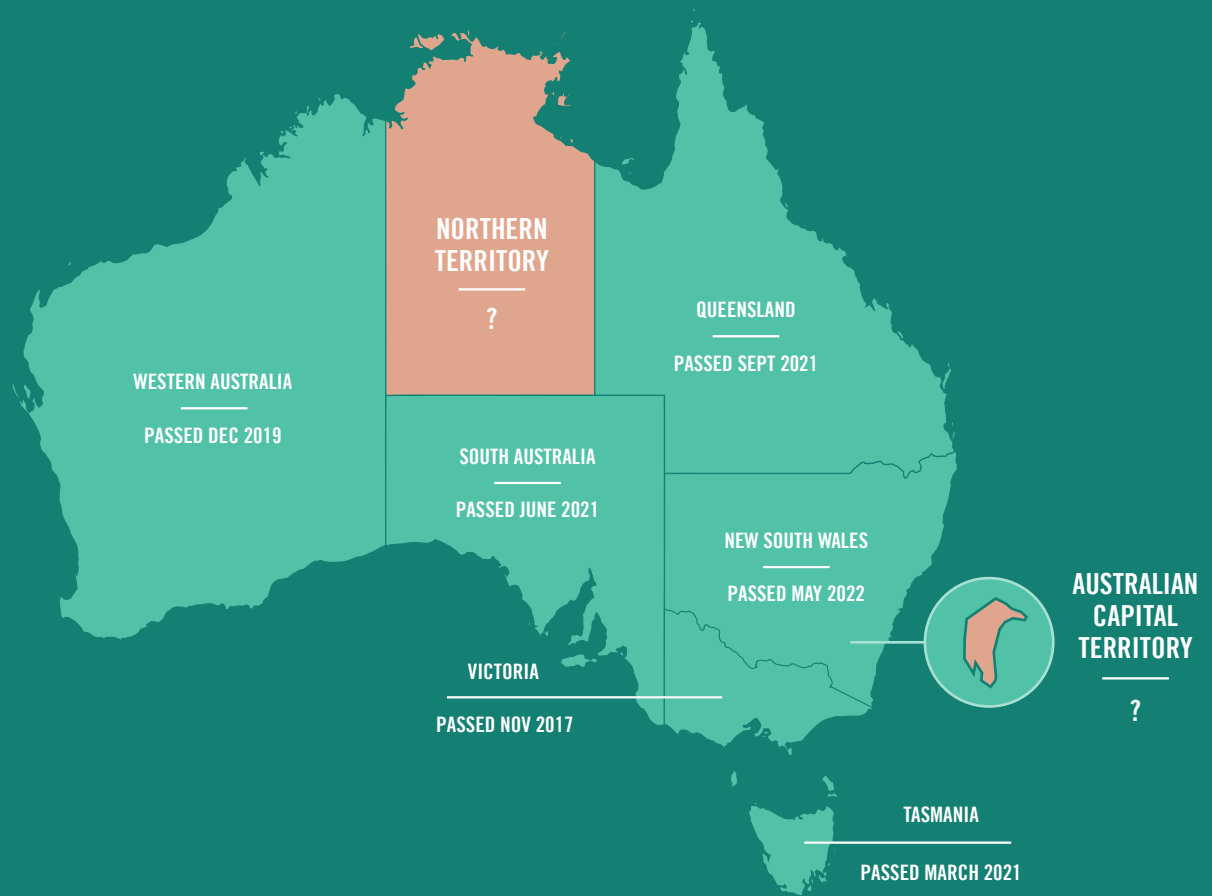


Scan or click the QR code to hear Professor White explain why evidence-based policy making is so important.

40. Ben White, Interview with Go Gentle Australia for the documentary film Fatal Fraud, July 2019 – https://www.gogentleaustralia.org.au/fatal_fraud

All states have now passed VAD laws

Why not the territories?



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

HEALTH MINISTER STEPHEN WADE DURING SOUTH AUSTRALIA'S PARLIAMENTARY DEBATE