Go Gentle Australia

State of VAD

Voluntary Assisted Dying
in Australia & New Zealand

2024

Introduction

Go Gentle Australia is proud to present the first annual *State of VAD* report.

In 2019, Victoria became the first Australian state to implement voluntary assisted dying (VAD). Over the next five years, laws were passed in every other state, the ACT and New Zealand. The Northern Territory is now the only jurisdiction yet to pass a law.

With VAD available to the vast majority of eligible Australians and New Zealanders, this *State of VAD* report is an opportunity to reflect on how VAD is working in practice, and how systems are supporting individuals, families and health professionals.

It presents an evidence-based 'snapshot' of VAD across the trans-Tasman. For the first time, it collates data from each jurisdiction's oversight bodies in one place. It also draws on data from our annual Australian *Voluntary Assisted Dying Survey*, as well as interviews with dying people and their families and health professionals, to present as complete a picture as possible.

In compiling this report we had to contend with an imperfect data set. Inconsistent data and time periods between jurisdictions are largely the result of different reporting requirements. Recent work to agree to a minimum data set will assist future reports. However, there is still more to be done to ensure that consistent and comparable data across jurisdictions are available to better identify areas for system improvements. Any comparisons made in this document are for this purpose.

We would like to acknowledge and thank the oversight bodies of each jurisdiction for their commitment to supporting and improving VAD services and for their transparency in publicly reporting on the performance of their respective services.

The NSW data included here is interim only and based on the initial three months of operation. Other jurisdictions expect updated data to be released in the months following this report. A report like this one can only ever be a snapshot at a particular point in time. This report has relied on the publicly available data as at July 2024.

We trust this report will prove a useful resource for those seeking to understand how VAD is fulfilling its aims and what can be improved.

Andrew Denton
Founding Director

Dr Linda Swan
CEO

Foreword

End-of-life discussions are hard. Most of us don't feel comfortable raising questions about 'what do I want *if*...'

The healthier we are, the more we feel it is unnecessary; the sicker we are, the more we feel uncomfortable.

We raised these issues a decade ago in our Grattan Institute report *Dying well* where we highlighted the need to promote and make these conversations easier. We also highlighted the importance of improving palliative care to ensure that good services were available everywhere, for everyone, when needed. Unfortunately, a recent report from the Australian Institute of Health and Welfare showed that less than half of those identified (statistically) as potentially benefiting from palliative care actually received specialist care, showing just how far we need to go.

In addition to raising how much intervention I want at the end of life, discussions also need to raise what are my thoughts and preferences about voluntary assisted dying (VAD)? Will my general practitioner affirm it as a legitimate option if and when I raise it, and facilitate that path if I elect it? What if I'm already in residential care? Will my new home, for that is what it is, make the VAD choice easy for me?

Australia's path to implementing VAD was slow and tortuous before Victoria became the first state to legislate successfully in 2017, initiating a scheme with numerous safeguards to secure passage. Other states – and the ACT – had an easier road following Victoria's precedent, but still objectors forecast dire consequences if legislation passed.

Importantly, all states set up monitoring processes to test predictions against reality and to assess what happened following implementation of the new schemes. Who is availing themselves of the VAD option? What are their reasons? And how does the option work in terms of accessibility and timelines? This report shows that none of the dire predictions made during legislative debates on VAD have eventuated.

We are still in the early stages of implementing VAD in Australia. Although each state has published reports on progress, this is the first collection of information from across Australia and New Zealand. The report is data rich, enabling us to answer some of those hypothetical questions that were raised during passage of the enabling legislation.

The legislative debates about VAD focused attention on all aspects of end-of-life care, and often led to increased investment in palliative care. As this report shows, and contrary to some claims, palliative care and VAD are not antithetical. However, many palliative care providers still act as if they are, making the path from one to the other disjointed and difficult to navigate. Legislation in some states strictly precludes any provider raising VAD as an option, again making the path harder and slower for patients and their families.

Other legislation, this time at the Commonwealth level, creates barriers to the use of modern technology – such as telehealth – to discuss VAD and this especially discriminates against people in rural and remote Australia, or in residential aged care.

This *State of VAD* is forward-looking: it describes what is, but it also looks at where anomalies might be addressed and improvements made. It is a very welcome addition to the literature on VAD and is commended to all interested in this issue.

Professor Stephen Duckett
AM FASSA FAHMS FAICD
Co-author of *Dying well* 2014

Overview

This report is about voluntary assisted dying (VAD) in Australia and New Zealand; how laws are operating and how well they are fulfilling their aims.

In the decade since the Grattan Institute published its landmark *Dying well* study,[1] little has changed in how most of us experience the end of life. Many believe that our dying is still overly medicalised and institutionalised. We disproportionately spend our last days in hospitals and aged care, despite our stated wish to die at home, supported by family and friends. The critical issue remains autonomy and choice.

However, one major reform has occurred. VAD is now legal in New Zealand, in every Australian state and soon in the ACT. It is offering people with a terminal illness choice and control over the timing and circumstances of their death and reducing their suffering.

According to publicly available data, since VAD first became legal in Victoria in June 2019, more than 7,200 terminally ill people in Australia and New Zealand have sought to access this end-of-life choice and 3,242 have died using a VAD substance, supported by more than 1,200 health professionals.

Any legislative framework for VAD must balance safeguards with the need for an accessible service for dying people. Evidence from each jurisdiction's independent oversight body shows that, overall, our VAD laws are meeting these goals. They are working safely; only terminally ill people who meet strict eligibility criteria are able to access VAD.

What's more, people's VAD choices are being supported and respected by health professionals demonstrating a deep level of compassion and care. Staged implementation and training have prepared the health workforce, and well-executed support services are guiding applicants through the process. There are many stories of health professionals going above and beyond to ensure terminally ill people and their families get the support they need.

However, with any significant reform there are challenges.

For people seeking VAD, between 30 and 50 per cent who start the process do not complete it (for various reasons including dying, being deemed ineligible or changing their mind). A better understanding of this non-completion rate will help determine if there is an imbalance between safeguards and accessibility for those who need it.

In addition, around one in five people who are ultimately found eligible die before they can administer the substance. This may be because they make a conscious choice not to proceed with VAD. However, different factors like loss of capacity may also be at play. We need more research to understand if these figures are a sign that process improvements are needed.

A handful of reforms will address these issues:

- **Streamline complex bureaucratic processes** to be less burdensome for dying people
- **Recognise VAD as an option within high-quality end-of-life care** and include it in relevant clinical standards and guidelines
- **Reform the Commonwealth Criminal Code** so those living outside Australia's major cities can discuss VAD via electronic communications and telehealth when needed
- **Grow the VAD health workforce** to meet growing awareness of and demand for VAD care; and ensure health professionals receive fair compensation for their time and skills
- **Help raise awareness of the VAD option** by allowing clinicians to have open and inclusive end-of-life conversations with their patients
- **Produce clear guidance** to individual practitioners, hospitals, hospices and aged care facilities so they understand their legal and ethical obligations to the people in their care

[1] Swerissen et al (2014)

- **Provide culturally safe resources and services** for First Nations peoples and those from culturally and linguistically diverse backgrounds.

Some of these initiatives require changes to existing legislation; many can be dealt with through policy responses. None of these reforms risks compromising the safeguards and consensus that underpin the model of VAD operating in Australia and New Zealand. All would help ensure that voluntary assisted dying remains accessible and equitable for the terminally ill people who want this choice.

About Go Gentle Australia

Go Gentle was founded in 2016 by broadcaster Andrew Denton. We are a charity working nationally to promote choice at the end of life, including the option of voluntary assisted dying.

Our vision is an Australia where we all are empowered to choose the end-of-life care that is right for us. We have been instrumental in passing voluntary assisted dying laws in all six states and the ACT and are now focused on supporting improvements to VAD care.

‘It feels civilised. A civilised way of leaving this earth. It has taken away the panic.’

Lynette Gelsomino, VAD applicant Victoria, with VAD practitioner Dr Nick Carr.

Photo: Julian Kingma

Contents

Key findings

1. **VAD laws are working safely and as intended** with a high level of compassion, care and integrity. Without exception, they are operating within the strict eligibility criteria and safeguards determined by parliament. The compliance rate with the administrative aspects of the VAD process is close to 100%.

2. **Awareness of and demand for VAD are growing.** Since 2019, more than 7,200 Australians and New Zealanders have sought VAD assessments and more than 3,200 people have died using a VAD substance.

3. **1,200 healthcare professionals have completed VAD training across Australia and around 140 are participating under the government SCENZ scheme in NZ**, yet more need to be encouraged – and appropriately paid – to take part in VAD care and meet growing demand.

4. **Restricting health professionals' conversations about VAD is impeding access.** 'Gag clauses' in some jurisdictions prevent practitioners from initiating conversations about VAD and are compromising person-centred care and informed consent.

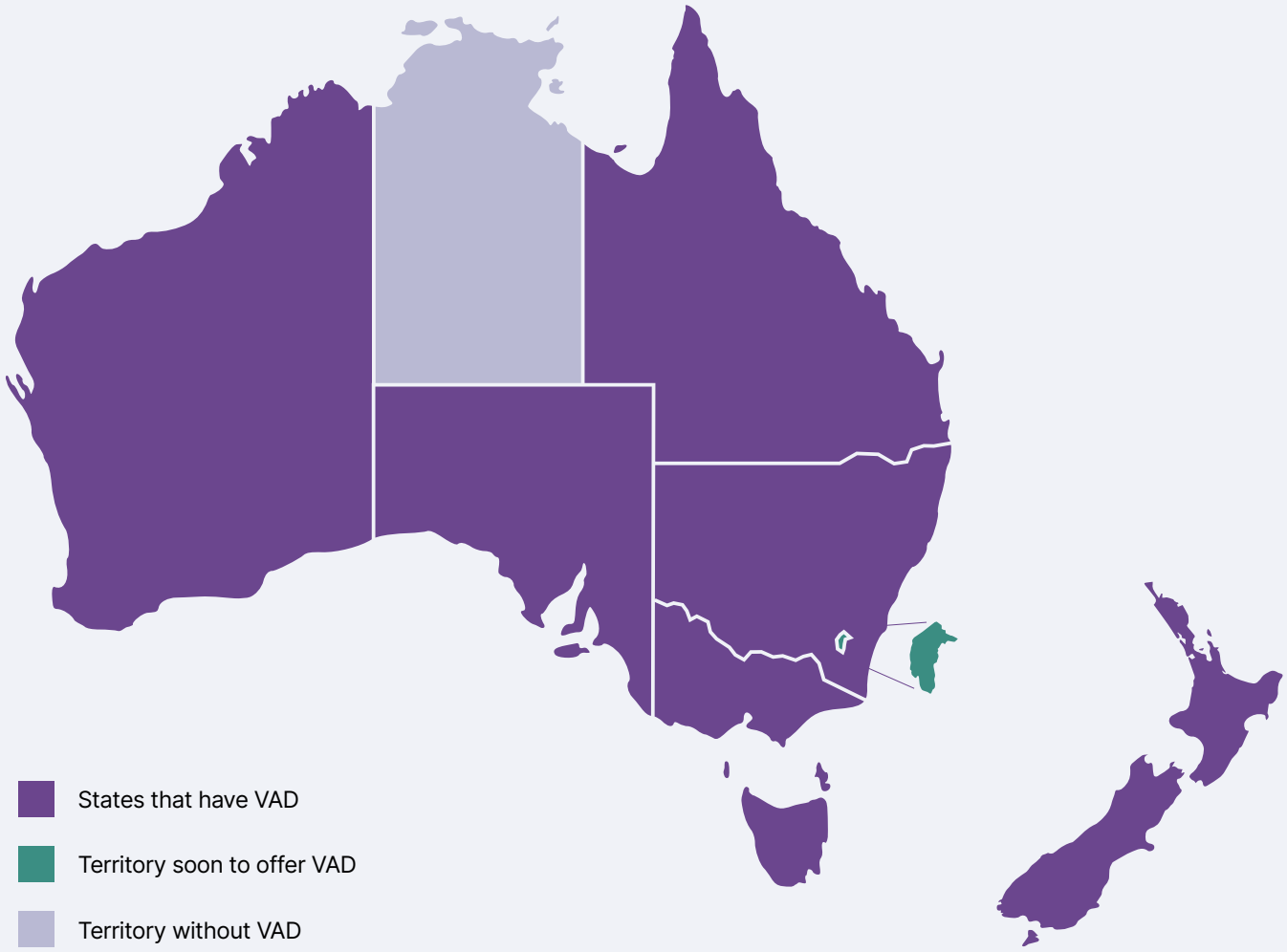
5. **Procedural elements, some intended as safeguards, are impeding access.** These include overly burdensome specialist and residency requirements, inadequate guidelines for non-participating practitioners and institutions, and, in Australia, a Commonwealth prohibition on using electronic communications in the VAD process.

6. **Sustainability of VAD services is uncertain.** While resourcing differs between jurisdictions, heavy workloads and lack of appropriate remuneration for participating health professionals must be addressed.

7. **There are strong intersections between VAD, palliative and end-of-life care.** There is an opportunity to better integrate VAD into existing care, to the benefit of all involved.

8. **Further work is needed to align VAD data sets throughout Australia and New Zealand.** Consistent reporting requirements and an improved minimum data set will allow deeper insights into the way VAD is operating and support a growing body of research.

VAD in Australia & New Zealand



Timeline

VAD laws have passed in New Zealand and all Australian states and territories except the Northern Territory. Each law has required a 12-18 month implementation period before taking effect.

VIC
- **Nov 2017** passed
- **June 2019** implemented

WA
- **Dec 2019** passed
- **July 2021** implemented

NZ
- **Nov 2020** referendum
- **Nov 2021** implemented

TAS
- **Mar 2021** passed
- **Oct 2022** implemented

SA
- **Jun 2021** passed
- **Jan 2023** implemented

QLD
- **Sept 2021** passed
- **Jan 2023** implemented

NSW
- **May 2022** passed
- **Nov 2023** implemented

AUST
- **Dec 2022** Territory rights restored

ACT
- **Jun 2024** passed
- **Nov 2025** implemented

NT
- **July 2024** NT expert panel presents report

7,208
terminally ill people have sought access to VAD

3,242
have died using a VAD substance

1,350
health professionals are assisting VAD applicants

Snapshot

	Australia ^	New Zealand ^
VAD applicants	5338 †	1870
VAD deaths	2467	775
of all deaths in population	~1%	~1%
Average age of applicants	73	65+*
Gender: Male %	56	48.3
Cancer as primary diagnosis %	72.6	68.5
Accessed palliative care %	79.4	76
Administration decision % • self • practitioner **	 51 49	 8 92***
No of VAD health practitioners (incl nurses)	1213	137 ††

^ totals and averages derived from available data
† approximation only
†† currently registered to provide VAD
* 76.9% of applicants were aged 65+
** definitions of practitioner administration differ between jurisdictions
*** correct to 1 March 2023

1. VAD in Australia

1.1 The Australian model

Australia's VAD laws are among the strictest in the world, following a model that limits medical assistance to die to adults with decision-making capacity who are in the final stages of a terminal illness and suffering intolerably.

Each law came about after significant public consultation and parliamentary inquiry, building on the strengths of those that came before. The result is similar, but not uniform, legislation across six states and the ACT.

The Australian model requires that an eligible person:

- Be aged 18+
- Be terminally ill, suffering intolerably and approaching the end of life
- Be assessed as eligible by two medical practitioners (or one medical practitioner and one nurse practitioner in the ACT)
- Make at least three separate requests for VAD, including a written request
- Have decision-making capacity throughout the process
- Be referred to a specialist physician if their decision-making capacity is in doubt
- Be acting voluntarily and without coercion
- Meet residency requirements.

The Australian model has other hallmarks:

- Mandatory training for VAD practitioners
- Specialist pharmacy, care navigation and support services in each jurisdiction
- Access schemes for people living in rural and remote areas
- Offences for wrongdoing and protections for health professionals acting in good faith
- The right to opt out or conscientiously object for health professionals
- Obligations for health institutions to not obstruct VAD (in South Australia, Queensland, New South Wales and ACT)
- Independent oversight bodies, to which clinicians must report throughout the process to ensure every case adheres to the law
- Statutory reviews of each law; Victoria's five-year review and Western Australia's three-year review are underway.

Recent developments

May 2022 NSW passes a VAD law, the final Australian state to do so

Dec 2022 Australian Parliament passes the Restoring Territory Rights Bill, overturning a 25-year ban on the Northern Territory and Australian Capital Territory making their own VAD laws

Sept 2023 VADANZ, the multidisciplinary peak body for VAD health professionals, launches at Go Gentle's inaugural trans-Tasman Voluntary Assisted Dying Conference

Jun 2024 The Australian Capital Territory passes a VAD law, removing time frames to death and allowing experienced nurse practitioners to assess patients alongside doctors

Jul 2024 A Northern Territory expert panel delivers a community consultation report outlining what a VAD law in the Territory might look like

Oct 2024 Second Go Gentle trans-Tasman Voluntary Assisted Dying Conference takes place in Brisbane

The VAD process*

* steps may vary slightly between jurisidictions

Breakdown by jurisdiction

	VIC	WA	TAS	SA	QLD	NSW ^
Law commenced Reporting period Data correct to	June 2019 4 years 30 June 2023	July 2021 2 years 30 June 2023	Oct 2022 8 months 30 June 2023	Jan 2023 14 months 31 March 2024	Jan 2023 15 months 31 March 2024	Nov 2023 3 months 29 February 2024
No of first assessments	2035	841	66	340	1749	408
No of VAD deaths	912	446	25	146	808	131
% of all deaths in population	0.65	1.4	0.5 #	1.0	1.6*	0.8 ##
Median age	74	74	72	73	73	70-79
Gender % (M)	54	58.4 †	59	54	56	56.9
Cancer as primary diagnosis %	76	70.7 †	66	75 ††	77	71.1
Applicants also receiving palliative care	81	85.7 †	71 ~	82 †††	77.5 ††††	not yet published
Administration decision % • self • practitioner	 85 15	 19.7 80.3	 not published**	 86 14	 33.5 66.5	 29.7 70.3
No of VAD health practitioners (incl nurses)	347	97	67	74	378	250

^ NSW has released an interim report based on selected data for 3 months
# estimated VAD deaths over 8 months compared to total deaths over 12 months
estimate based on 2022 ABS data noting excess mortality relating to COVID-19
~ of people who contacted the care navigator service and inquired about VAD

* based on data for the 2023 calendar year and Qld registry of births deaths and marriages data for 2023
** definitions of self and practitioner administration differ in Tasmania

† of eligible first assessments
†† of VAD deaths
††† at time of first assessment or in past 12 months
†††† at first assessment or previously

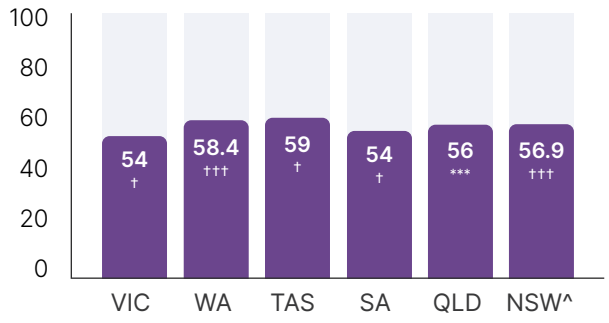
1.2 Who is accessing VAD in Australia?

The terminally ill adults who seek VAD are of all ages and backgrounds; however, a typical applicant is aged between 70 and 79 years, more likely to be male and has a cancer diagnosis[2].

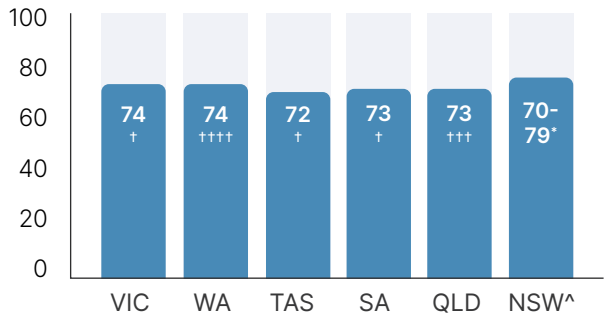
Data also shows almost 70 per cent of applicants were born in Australia, in line with the general population[3], and the vast majority (>90%) spoke English as their preferred language. Between 0.5 and 2 per cent of applicants required the services of an interpreter.

There is emerging evidence from some states that the proportion of people accessing VAD from rural and regional areas is higher than would be expected from general population distribution. In Victoria 23 per cent of people live outside Melbourne yet regional Victorians made up 36 per cent of VAD first assessments. In NSW, the figure is even higher – 30 per cent of the population lives outside greater Sydney yet the first three months of data show around two-thirds (65.2%) of VAD assessments occurred outside the Sydney metro setting. These figures raise questions about why this may be. Hypotheses include that people living in rural and regional areas are, on average, older than those in major cities and tend to have poorer health outcomes[4]. Reduced access to health services that could support dying at home may be a factor. There is also anecdotal evidence that country people are more pragmatic and comfortable with the concept of assisted dying than their city counterparts.

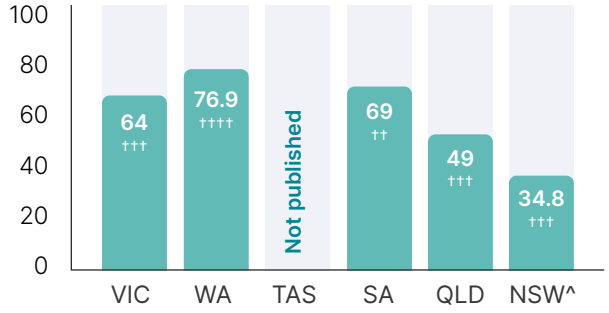
VAD by gender - Male %



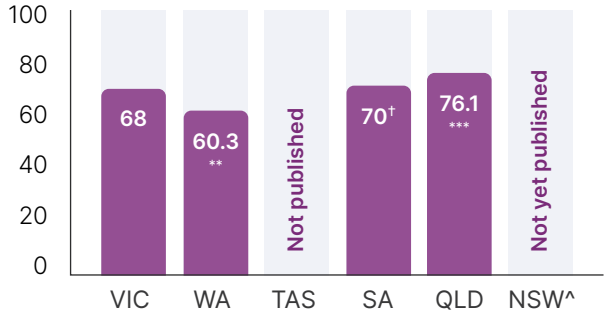
VAD by age (median)



VAD by location - Metro %



VAD by country of birth - Australian born %



^ based on interim data for 3 months
* average age range published
** of applicants eligible at first assessment
*** of people at first assessment (data based on first six months)

† of applicants
†† of VAD deaths
††† of first assessments
†††† of eligible first assessments

[2] Vic VAD Review Board (2021-22, 2022-23); WA VAD Board (2021-22, 2022-23); TAS VAD Commission (2022-23); SA VAD Review Board (2022-23); QLD VAD Review Board (2022-23); NSW VAD Review Board (28 Nov 2023-29 Feb 2024)

[3] Australian Bureau of Statistics (2024)

[4] Australian Institute of Health and Welfare (2024)

People who have sought VAD appear to be well educated: in jurisdictions where this data is published, around 63 per cent of applicants aged 65 or older had completed secondary education (year 12), compared to 34 per cent of this group in the general population.[5]

A tiny proportion of all deaths

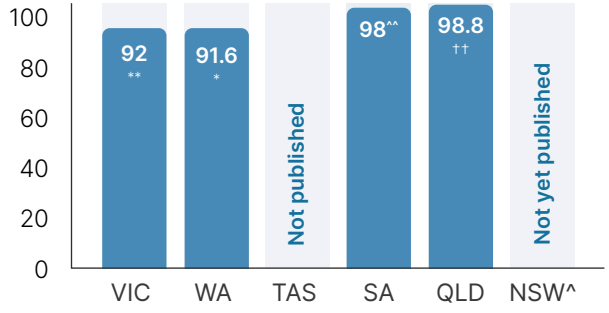
Assisted deaths make up a small fraction of all deaths in population each year. In Tasmania, for the first eight months it is estimated at around 0.5 per cent of all deaths[6]; in Victoria 0.65 per cent.[7] In NSW, estimates based on early data put it at less than 1 per cent, South Australia roughly 1 per cent[8]; Western Australia 1.4 per cent[9] and Queensland 1.6 per cent.[10] This range is consistent with other countries where assisted dying is lawful.[11]

Indigenous Australians

Aboriginal and Torres Strait Islander people are seeking assisted deaths, but in small numbers. Not all jurisdictions publish this data.

There are likely multiple reasons why Indigenous people are underrepresented[12] including that VAD may not align with spiritual and cultural beliefs. Significant consultation with Aboriginal community representatives is ongoing and Queensland, Western Australia and NSW have produced resources for Indigenous communities.[13] In South Australia, an additional VAD Review Board member

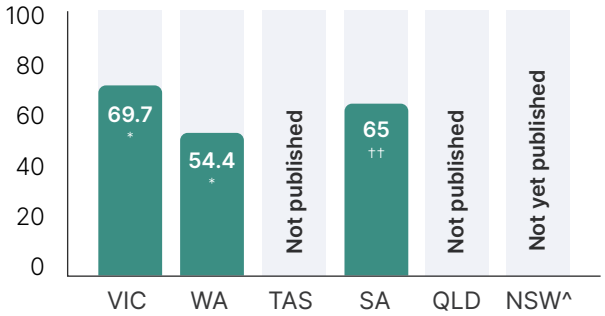
VAD by preferred language - English %



^ based on interim data for 3 months
^^ data provided by Review Board

* of applicants eligible at first assessment
** of applicants
†† of people at first assessment (data based on first six months)

VAD by educational attainment - high school or above %



First Nations Australians' access to VAD

First Nations Australians as	VIC	WA	TAS	SA	QLD	NSW^
% of VAD applicants	1.0	1.7**	not published	0.53^^	1.4***	2.5*
% of total state population	1.0	3.3	5.4	2.4	4.6	3.4

^ based on interim data for 3 months
^^ data provided separately by Review Board

* of first assessments
** of those eligible at first assessment
*** of first assessments/based on the first 6 months of operation

[5] Australian Institute of Health and Welfare (2023)
[6] TAS VAD Commission (2022-23)
[7] Vic VAD Review Board (2019-23)
[8] SA VAD Review Board (2022-23)
[9] WA VAD Review Board (2022-23)
[10] QLD VAD Review Board (2022-23)
[11] In NZ the rate is <1%, in Belgium 3.1%, Canada 4.1% and The Netherlands 5.1%
[12] Lewis, S, et al. (2002)
[13] Western Australia Health (2021); Queensland Government (2022); NSW Health (2023)

has been appointed to represent the needs of Aboriginal and Torres Strait Islander people. SA Health is planning to work with Indigenous stakeholder groups to co-design a culturally safe VAD model of care.[14]

Method of administration

In all jurisdictions, a person may either take the VAD medication themselves (self-administration) or be administered the medication by a health professional (practitioner administration). However, only in NSW and the ACT can a person independently choose their preferred method.[15] In most other jurisdictions, self-administration is the default method – only if the person cannot swallow or ingest the substance, or if self-administration is otherwise deemed inappropriate in consultation with the healthcare team, can practitioner administration be considered.

Western Australia's law restricts how much assistance a person may receive during self-administration. In most other states, a friend or carer may help prepare and mix the substance. WA does not permit this and evidence is emerging that some people may be dissuaded from self-administration as a result, which was not the legislation's intent.

Waller K et al. note that a primary reason for legalising VAD was to respect the autonomous choices of people at the end of their lives. To this end, only NSW and the ACT truly respect this autonomy by permitting people to freely choose their preferred method of VAD.[16] Data shows that in jurisdictions that offer more autonomy, significantly more people elect practitioner administration.

Self versus practitioner administration by jurisdiction

	VIC	WA	TAS	SA	QLD	NSW^
Self-admin %	85	19.7	not published	86	33.5	29.7
Practitioner admin %	15	80.3	not published	14.5	66.5	70.3

^ based on interim data for 3 months

States with least autonomy around administration decision

[14] SA VAD Review Board (2022-23b)

[15] Waller K et al. (2023)

[16] ibid

Assisted dying gave me my life back

Victorian Alex Blain, 28, chose VAD in January 2021, after 19 rounds of chemotherapy, surgery and radiotherapy to combat CIC Dux Ewing's Sarcoma, an aggressive, rare and fatal cancer. Three days before he died, Alex wrote that VAD 'gave me my life back just as I started dying'.

'I handed my treatment and body over to medical professionals for over a year and in many ways lost autonomy over my body,' he said. 'I feel empowered and now, as it is getting towards the end, I know that I have control back. I can show myself compassion and choose not to die of cancer. It is a small thing but the peace of mind it has created is immeasurable.'

Alex said that applying was straightforward because he fulfilled all eligibility criteria, although VAD 'needs to be more widely talked about'. His family said the respect and compassion from medics meant Alex left every appointment relieved and with 'a spring in his step'.

'The control and the ability to find peace gave him comfort,' his fiancée Liz said. 'I've come to the conclusion that VAD has very little to do with death and a lot to do with life.' [17]

What is a good death?

A systematic review in *The Lancet* in 2021 identified 11 conditions for a 'good death'. [18]

1. Relief from physical pain and other physical symptoms
2. Effective communication and relationship with health-care providers
3. Performance of cultural, religious or other spiritual rituals
4. Relief from emotional distress or other forms of psychological suffering
5. Autonomy with regards to treatment-related decision making
6. Dying at preferred place
7. Not prolonging life unnecessarily
8. Awareness of the deep significance of what is happening
9. Emotional support from family and friends
10. Not being a burden on anyone
11. Right to terminate one's life

[17] Go Gentle Australia (2021)
[18] Zaman, M et al. (2021)

Time required to complete the process

The time that it takes to navigate the VAD process is person and situation specific and widely variable. All states except NSW and Tasmania require that a minimum 9-day period elapse between first and final request. In NSW, it is 5 days. The Tasmanian Act requires 96 hours (48 hours between the first and second request, and 48 hours between second and final request). In all jurisdictions these time periods can be waived if the patient is likely to die or cease to have decision-making capacity. The ACT law, which will come into effect in November 2025, includes no minimum waiting period, recognising that the time it takes to navigate the VAD process is already significant. The evidence of VAD in practice supports the ACT approach – data indicates that people typically take between 2 and 5 weeks to navigate the VAD application and assessment process.

Time taken to complete process

Days from	VIC	WA	TAS	SA	QLD	NSW^
first to final request/substance authorisation	16	13 †	17 †† *	23 ††	17.5 † *	not yet published
first request to substance dispensing	34 †	not reported	not reported	not reported	not reported	not yet published
first request to death	not reported	24 †	34 †† *	40 †† **	not reported	not yet published

^ based on interim data for 3 months
* based on data from the first 6 months of operation
** based on data from first 5 months of operation
† median number of days (drawn from the 2022-23 annual report)
†† average number of days (approximate)

Reasons for seeking VAD

1. A terminal diagnosis

The diagnosis of at least one disease, illness or medical condition that, on the balance of probability, will cause death within 6-12 months is the foundational reason for accessing VAD. The life-limiting condition must also be causing suffering that the person finds intolerable.

A primary cancer-related diagnosis is the most common reason for a VAD application. Across the country, almost three-quarters (72.6%) of those deemed eligible had terminal cancer; 12.5 per cent were diagnosed with a terminal neurological condition; and 6.3 per cent a terminal respiratory illness.

VAD applicants by life-limiting illness

	VIC	WA	TAS	SA	QLD	NSW^
Cancer %	76 †	70.7 ††	66 †	75 †††	77 †	71.1 ††††
Neuro %	9	13.7 †	13	14	7.5	17.1
Respiratory %	3	7.7	10	3	8	6.9
Other %	12*	7.9	11	8	7.5	4.9

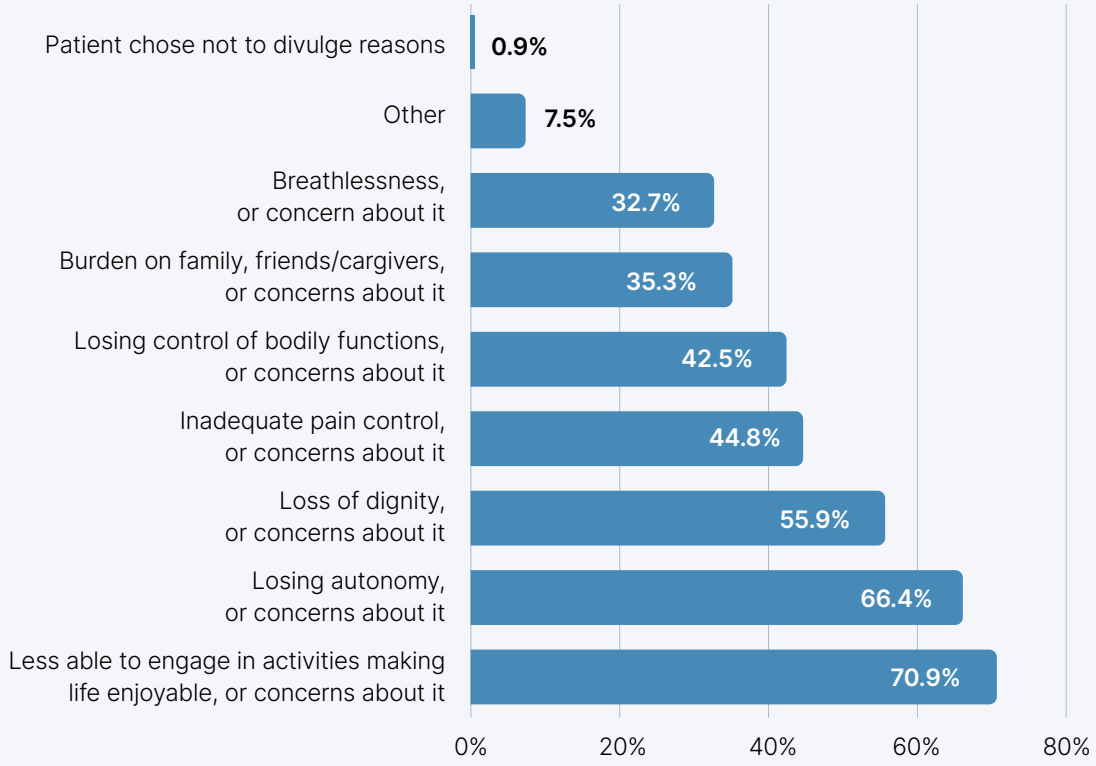
^ based on interim data for 3 months
* includes cases not yet assigned
† of people assessed as eligible
†† of patients found eligible at first assessment
††† of VAD deaths
†††† of people granted a substance authority

Around 7.7 per cent had 'other' terminal conditions, including congestive heart failure, end stage renal failure, peripheral vascular disease, advanced liver disease (excluding liver cancer), HIV/AIDS, end-stage diabetes, and other rare conditions such as scleroderma.

2. What constitutes intolerable suffering?

Western Australia is the only jurisdiction that publishes information on secondary reasons for seeking VAD, i.e. what is contributing to the experience of intolerable suffering? While not part of the eligibility assessment, applicants in WA are asked to choose motivating factors for requesting VAD from a list of options. Over two years, the most common responses were: 'being less able to engage in activities making life enjoyable, or concern about it' (70.9%); 'losing autonomy, or concern about it' (66.4%), 'loss of dignity, or concern about it' (55.9%), and inadequate pain control, or concern about it (44.8%).[19] It is important to understand that multiple answers are permitted and that, generally, these answers reflect a multiplicity of reasons for choosing VAD, all of which fall within the overall context that the person is dying of a terminal illness. This information is invaluable to better understand why some terminally ill people choose an assisted death, and we encourage all jurisdictions to collect and publish this data.

Patient reason for accessing voluntary assisted dying in WA since 1 July 2021
(taken from the WA VAD Board annual report 2022-23)



[19] WA VAD Board (2022-23a)

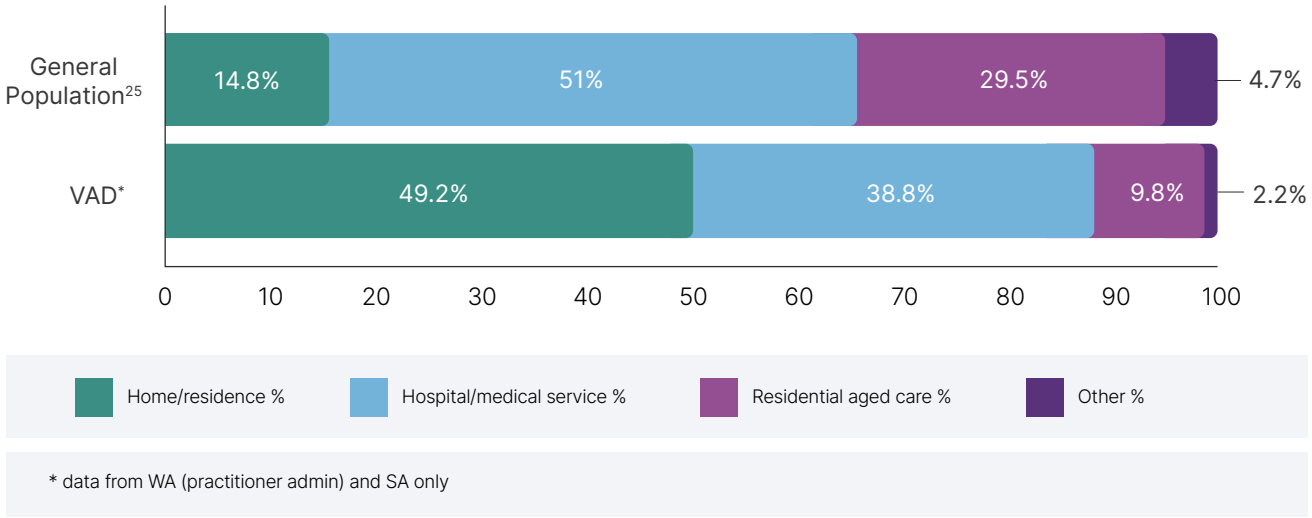
Place of death

The ability to die in a preferred place is an important condition of a 'good death'.[20] Up to 70 per cent of Australians say they would prefer to die at home, but few (15%) do so.[21] Around half of us (51%) die in a hospital and another 29 per cent die in residential aged care.[22] These outcomes have barely changed in the past ten years.

In contrast, around half of VAD practitioner administered deaths in Western Australia and half of all VAD deaths in South Australia took place at home.[23] In New Zealand, by comparison, more than 80 per cent of assisted deaths were at home.[24] We could see similar outcomes across Australia in time. In Queensland, for example, more than 85 per cent of VAD applicants were living at home (residence or retirement village) at the time of their first VAD assessment.

In an ageing population with an increasing number of deaths each year, the pressure to provide 'better' deaths will also grow. VAD is helping to 'de-medicalise' and 'de-institutionalise' dying, offering more Australians (especially older Australians), the choice to die well in the place they call home.

Comparison of place of death Australia



* data from WA (practitioner admin) and SA only

[20] Zaman, M et al. (2021)
[21] Swerissen, H et al. (2014)
[22] Australian Bureau of Statistics (2021)
[23] WA VAD Board (2021-22, 2022-23); SA VAD Review Board (2022-23). Data not available for other Australian jurisdictions.
[24] NZ Assisted Dying Service (2021-22); NZ Assisted Dying Service (2022-23); NZ Assisted Dying Service (2024)
[25] Australian Bureau of Statistics (2021)

Intersection with palliative and end-of-life care

Palliative and end-of-life care offer important services and support to manage a dying person's wellbeing, symptoms and comfort.[26] Across all jurisdictions that have published an annual report, between 71 and 86 per cent of people who requested VAD had accessed, or were accessing, a palliative care service. This number was similar in New Zealand. This intersection between VAD, palliative and end-of-life care is an opportunity for more collaboration and open discussions about how VAD choice can be incorporated into standard models of care at the end of life.

Support for families

The impact of VAD on grief and bereavement outcomes is largely unknown. VAD deaths involve planning and a known date and time of death, and evidence is emerging that the resulting bereavement – although not dissimilar to that following a natural death – may require additional support. Several respondents to the *National VAD Survey* highlighted the difficulties accessing VAD-informed grief and bereavement services.[27] The WA VAD Board has recommended the development of VAD-specific resources, practitioner guidance and referral pathways 'to ensure consistent and quality provision of grief and bereavement services to patients and families impacted by voluntary assisted dying.' [28]

Patient engagement with palliative care

	VIC	WA	TAS	SA	QLD	NSW^
% of VAD applicants receiving palliative care	81 †	85.7 ††	71 †††	82 ††††	77.5 †††††	not yet published

^ based on selected data for 3 months
† applicants
†† of eligible first assessments
††† of people contacting the care navigator service and inquiring about VAD
†††† at time of first assessment or in past 12 months
††††† at time of first assessment or previously

Palliative effects of VAD choice

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

Fiona Jane, Clinical Hospice Manager, Albany Community Hospice, WA[29]

[26] Australian Institute of Health and Welfare (2021)
[27] Go Gentle Australia (2024b)
[28] WA VAD Board (2022-23c)
[29] Go Gentle Australia (2022)

An assisted death: What families say

It was so unbelievably peaceful. We were in the garden, she was holding my hand. The sun was out. We all cried. But we knew this is what she wanted.

Nicole Lee, mother Sue Parker, motor neurone disease, chose VAD in Victoria in 2022.[30]

As he was telling us how much he loved us, he slipped away to the peace that he so desperately craved. It was a beautiful death. It was a death he wanted, and he never wavered in his decision.

Debra Millikan, partner Arnold Gillespie, cancer and other complications, chose VAD in South Australia in 2023.[31]

Once the decision was made, her demeanour changed to joy and a sense of great relief. The days that followed saw a celebration of her life with a BBQ, lots of stories, memories, humour, family, friends and plenty of whiskey. She died with a smile on her face.

Lorraine Doyle, mother Lola Hope Dickson, chose VAD in NSW in 2024.[32]

It is the humanity shown throughout that is of the foremost importance I think.

Daryl, whose brother had terminal cancer and applied for VAD in South Australia.[33]

Sue Parker with daughter Nicole Lee
Photo: Julian Kingma

[30] Go Gentle Australia (in press)
[31] Go Gentle Australia (2024)
[32] Lewis, BC, Blue Mountains Gazette (2024)
[33] SA VAD Review Board (2022-23a)

1.3 Who is providing VAD care?

A small number of authorised practitioners

The health workforce is key to ensuring the availability and sustainability of VAD. Doctors, nurses, social workers, pharmacists, psychologists and other allied health professionals are involved in providing VAD care; either directly, through assessment or substance administration, or through wrap-around support services.

In all states, only doctors are permitted to undertake the first and second formal eligibility assessments; the ACT is the only jurisdiction that allows an experienced nurse practitioner to be one of the assessing practitioners (the second must be a doctor). As such, access to VAD is contingent on doctors' willingness to be involved.

While doctors hold a diversity of views about VAD, only a small number are participating. In Victoria, four years after the introduction of VAD, 347 doctors had registered to provide VAD services representing just 1.2% of the 30,124 licensed physicians in the state. In Western Australia, after two years, the figure was 90 (0.75%).[34]

The exceptions may be Queensland where after 15 months 378 clinicians (187 doctors, 191 nurses) have completed VAD training and become authorised practitioners,[35] and NSW where interim data covering the first three months of the law's operation indicate a significant recruitment of VAD practitioners (228 doctors, 22 nurses).[36]

Medical practitioners (doctors) trained, registered and providing VAD services.

(N.B. medical practitioners must meet professional qualification and eligibility requirements to be an authorised VAD practitioner).

	VIC	WA	TAS	SA	QLD	NSW^
	first 4 years	first 2 years	in the 8 months since the start of the Act	first 14 months	first 15 months	first 3 months
No. of Drs trained	347	90	33	74	187	228
% of total registered in state[37]	1.2	0.75	1.2	0.81	0.76	0.64
No. who have participated in a VAD case	208	68 *	16	57	108 †	not yet published
% who have participated in a VAD case	60	70.1	48	77	70	not yet published

^ based on interim data for 3 months
† based on first 6 months of data only
* acted as coordinating, consulting or administering practitioner

60%
of VAD-trained doctors go on to care for VAD applicants

80%
of non-VAD engaged practitioners said they would consider doing VAD training if the right supports were in place[38]

[34] Australian Government, Dept of Health and Aged Care (2024)
[35] QLD VAD Review Board (2022-23)
[36] NSW VAD Review Board (2024)
[37] Australian Government, Dept of Health and Aged Care, Health Workforce Data (2024)
[38] Go Gentle Australia (2024b)

Data from jurisdictions that have published annual reports show that around 60 per cent of VAD-trained doctors go on to care for VAD applicants. Incentives must be in place to ensure more clinicians undertake training and engage with VAD services. Eighty per cent of non-engaged practitioners who responded to the *National VAD Survey* said they would consider doing VAD training and provide VAD care if the right workplace supports were in place.[39] These supports included caseload management, pastoral care, mentoring for newly qualified practitioners and professional development.

Recognising the need, South Australia is developing a Medical Practitioner Education and Training Strategy to 'promote increased medical practitioner registration, training and participation in voluntary assisted dying and outline actions to ensure the sustainment of the existing, invaluable workforce.' [40]

GPs

The high representation of general practitioners involved in VAD reflects the important role that GPs play in end-of-life care for people living with a life-limiting illness.

There are comparatively fewer non-GP specialists who have completed VAD training. This makes access to authorised practitioners significantly more difficult for people in Victoria where one of the assessing practitioners 'must have relevant expertise and experience' in the disease, illness or medical condition that has led to the VAD request.

Number of GPs

	VIC	WA	TAS	SA	QLD	NSW^
GP	206 †	45 ††	13 ††	37 †	not published	not yet published
% of VAD practitioners	59.4	44.6	81	50		

^ based on interim data for 3 months
† of those trained
†† of those trained and participating

Number of VAD-trained specialists*

	VIC	WA	TAS	SA^	QLD	NSW^
No. of VAD trained specialists (excl GPs)	141	56	not published	37	not published	not yet published
Oncology	54	4	not published	9		
Neurology	14	4	not published	4		

* physicians can hold more than one speciality registration
^ accurate to 30 June 2024 on advice from Review Board

[39] Go Gentle Australia (2024b)
[40] SA VAD Review Board (2022-23c)

Clinical supervision and support

Attracting and retaining workforce was a major concern for many clinicians and others who responded to the *National VAD Survey*.[41] Those already working in VAD said they had the knowledge and skills to deliver good care, but they valued ongoing support. Communities of practice and workplace resources were all highly valued as were mentoring and supervision. A large proportion (80%) of non-VAD practitioners who responded to the survey indicated a willingness to undertake VAD training in future if the right supports were in place. The most commonly cited incentive was that VAD training is made more accessible, with a focus on time, location and financial subsidisation.[42]

Nurse involvement

In all states, only doctors are permitted to undertake first and second formal assessments of patients for VAD eligibility. However, four states (WA, TAS, QLD and NSW) permit a nurse practitioner to administer a VAD substance. In Queensland and Tasmania, this role is extended to registered nurses.

The ACT is the only jurisdiction where a nurse practitioner will be able to participate in formal eligibility assessments and administrations.

As important as saving lives

'It's the most humane thing that's happened in the world,' says 75-year-old Margaret River local Barry Walton of Western Australia's VAD law.

Diagnosed with terminal bowel cancer that has spread around his body, Barry knows exactly where he will be when he dies. 'At home on my veranda, in the sunshine, looking at the peppermint trees.'

He is adamant that his VAD coordinating doctor Sandra Rennie will be there. Dr Rennie, an emergency medicine physician, sees her patients after hours and on weekends. Barry says: 'She's my angel of mercy, a wonderful person. She's taken away my fear. What she does is just as important as saving lives.' [43]

Number of VAD-trained nurses

	VIC	WA	TAS	SA	QLD	NSW^
Nurse practitioners	n/a	7	unknown	n/a	22	22
Registered nurses	n/a	n/a	23	n/a	169	n/a
Total		**7**	**23**		**191**	**22**

^ based on interim data for 3 months

[41] Go Gentle Australia (2024b)
[42] Go Gentle Australia, (2024c)
[43] Go Gentle Australia (in press)

VAD support services

Without exception, the statewide support services, including care navigator and pharmacy services, set up in each state to help people and health professionals navigate their way through the VAD process have been acknowledged as success stories for their dedication, professionalism, integrity and compassion.

These services ensure people seeking VAD are quickly put in touch with health professionals who can help them and prepare them for the safe and informed administration of the VAD substance. They also offer vital logistical and pastoral support to VAD practitioners. All oversight bodies have recommended ongoing review of funding for these services to ensure they are sustainable, can meet demand, and that individual practitioners, patients and families are supported.

Statewide services: Kind and meticulous

We all know the care navigators have our back. They are the glue that holds the voluntary assisted dying service together. If it wasn't for them, I wouldn't do this work.

GP, Western Australia.[44]

My wife and I were overwhelmed with this experience. Kind and meticulous pharmacists who ensured I understood the process. Demonstrations and written information outstanding. Thank you for the opportunity to end my suffering on my own terms with dignity… I will remember you both, as my wife will, for your act of humanity and kindness.

VAD applicant, Victoria.[45]

Our fears and concerns were totally taken away by our first meeting with our care navigator. So respectful, so gentle, caring and compassionate. Every contact we had with this service was thoughtful, entirely cognisant of the legal requirements.

Family member, personal reflection, South Australia.[46]

My husband was able to access VAD this year after 17 months of unsuccessful treatment and management of cancer. He died peacefully and with dignity on his own terms, and he was and I remain grateful for having access to this service. All the staff involved in the process were professional and caring and respectful.

Partner of VAD applicant, Tasmania.[47]

[44] Go Gentle Australia (in press)
[45] Vic VAD Review Board (2022-2023c)
[46] SA VAD Review Board (2024)
[47] TAS VAD Commission (2022-23b)

1.4 Barriers to access and equity

Statutory bodies that oversee VAD have reported significant barriers to access. In jurisdictions that have issued annual reports, up to half of all people who begin the VAD request and assessment process do not complete it, and around one in five who are deemed eligible die without administering a VAD substance. VAD is person directed and people will move through the process at their own pace. Oversight bodies have pointed out[48] that it should not be assumed that every person who commences the process will ultimately choose to die from VAD. Patients are able to pause or withdraw from the process at any time for various reasons and the data necessarily includes applicants who are yet to complete all stages of the process.

However, the non-completion rates do suggest the VAD application process may be overly complex for dying people and that many applicants start the process too late. A better understanding of the barriers to access and streamlining the bureaucratic process could help deliver the aims of VAD laws, especially for marginalised Australians and those living in regional, rural and remote areas.

Awareness of VAD

Awareness of VAD as an available end-of-life option is increasing, albeit at different rates across jurisdictions.[49] In Victoria and Western Australia, where VAD has been available for the longest, the number of people engaging with VAD services (first assessment) between 2021-22 and 2022-23 grew by around 4 per cent in Victoria and 23 per cent in Western Australia.

Of the 180,000+ deaths across Australia each year, the majority are predictable and can be planned for.[50] Awareness of VAD as a legal end-of-life option helps people make informed decisions and supports autonomy and choice.

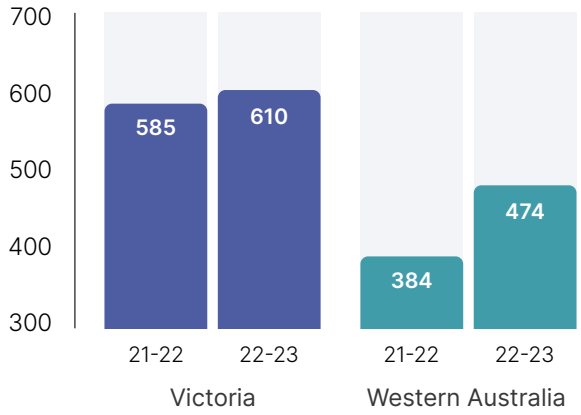
In its 'Strategic Plan 2023 to 2026', Western Australia's VAD Board has prioritised awareness raising and understanding of VAD among the public and health practitioners.[51] South Australia's VAD Review Board has similarly committed to updating written resources to support patients, families, medical practitioners, and staff,[52] and Queensland's VAD Review Board has committed to continue community and stakeholder engagement.[53]

Access to VAD health professionals

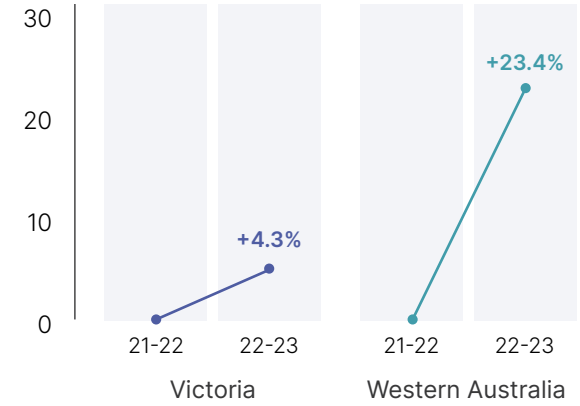
VAD applicants, families and carers have highlighted the difficulty in finding a doctor trained and willing to assess eligibility[54] – especially in rural, regional and remote areas. Interviews with 33 family members of Victorians who accessed VAD found the main hurdle was finding doctors willing to assist people.[55] This sentiment was replicated in the *National VAD Survey*.[56]

Relatively few medical practitioners are VAD-qualified.[57] In Tasmania's north west, for example, which has a

Increase in first assessments 2021-22 to 2022-23[58]



% increase in first assessments



[48] Go Gentle Australia (July 2024)
[49] Go Gentle Australia (2024b)
[50] Violet Initiative (2024)
[51] WA VAD Board (2022-23b)
[52] SA VAD Review Board (2022-23a)
[53] QLD VAD Review Board (2022-23c)
[54] Rutherford, J et al. (2021); McDougall,R, Pratt, B, (2020); Go Gentle Australia, National VAD Survey (2024)
[55] White, B.P, et al. (2023)
[56] Go Gentle Australia (2024b)
[57] Australian Government, Dept of Health and Aged Care, Health Workforce Data (2024)
[58] Vic VAD Review Board (2022-23); WA VAD Board (2022-23)

population of almost 120,000 people, there were only two doctors trained to provide VAD as at 30 June 2023.[59]

In NSW, measures are in place to ensure patients are able to access VAD wherever they live in the state and significant resources have been invested in a central team of authorised visiting medical officers (VMOs) who regularly travel to see patients. This 'VMO model' is being watched with interest by other jurisdictions.

Access challenges are compounded by Commonwealth restrictions on using telecommunications and telehealth in the VAD process. Although jurisdictions navigate these restrictions in different ways, and all states offer rural access schemes, the time and travel investment required to see patients in-person is a challenge for both health professionals and state governments to maintain. While the number of VAD-trained health professionals around the country is slowly increasing, more clinicians must be encouraged to take up training to meet demand and ensure a sustainable workforce. Training more doctors, in particular, would mean fewer time pressures on conducting VAD assessments, a greater opportunity to develop the skill sets to provide high-quality care and more downtime between VAD cases for emotional support and self-care.[60]

Victorians face an additional hurdle. Their law requires that one of two assessing doctors must be a specialist in the person's illness – and that a third specialist opinion be sought for neurodegenerative illnesses where the prognosis to death is more than six months. This is a challenge given comparatively few specialists are VAD-trained, and discriminates against those with rare conditions and those living outside metropolitan areas.

VADANZ

An important voice for VAD health professionals

A new multidisciplinary peak body to champion the voice of voluntary assisted dying (VAD) health professionals was launched in 2023. VADANZ encourages VAD knowledge and expertise to be discussed and shared in Australia and New Zealand to deliver evidence-based, high-quality VAD care.

The peak body focuses on workforce sustainability, including proper remuneration for VAD professionals and the development of VAD-specific Standards of Care, similar to those that exist for palliative care.

Inaugural VADANZ president clinical oncologist Dr Cameron McLaren said workforce sustainability was key.

'Voluntary assisted dying across Australia and New Zealand is operating to extremely high standards with incredible care and compassion. However, its success is due, in large part, to the goodwill and dedication of a relatively small group of healthcare professionals who go above and beyond for their patients.

'Health professionals providing VAD need strong representation and an empowered voice to ensure the very best systems, standards and supports are in place so that patients receive the care they need. VADANZ will provide that voice.'

Dr McLaren said VAD provision was currently siloed and overly complex for both clinicians and patients. 'Many aspects are underfunded and poorly integrated with existing health services.

'This poses significant challenges. We must ensure VAD funding keeps pace with the work required, that the pipeline of participating clinicians is sustainable, and unnecessary barriers to access for patients are removed.'

[59] TAS VAD Commission (2022-23)
[60] Rutherford, J et al. (2021); McDougall,R, Pratt, B, (2020)

As the Victorian VAD Review Board has noted 'for applicants with mobility issues and those situated in regional and remote areas, this often requires extensive travel and delays to assessment. Deterioration of an applicant over this time may have further impact on their ability to complete an assessment process.' [61]

To address these shortfalls, several jurisdictions are looking at giving experienced nurses a greater role. Western Australia, Tasmania, Queensland and NSW already permit nurse practitioners to administer the VAD substance, while Queensland and Tasmania extend this role to registered nurses. When implemented at the end of 2025, the ACT law will be the first to allow experienced nurse practitioners to conduct one of the two formal eligibility assessments (the second must be done by a doctor). The ACT government justified the move on access grounds:[62]

> 'In a small jurisdiction like the ACT, with limited health resources and a relatively small workforce, imposing narrow or inflexible health professional qualification requirements is likely to restrict the pool of health professionals who are eligible to participate in voluntary assisted dying, which in turn may restrict a person's access to voluntary assisted dying.'

Western Australia, is similarly considering widening the practitioner pool.[63]

Limits on open discussions

Victoria and South Australia prohibit doctors from initiating conversations about VAD with their patients, drawing much criticism from health professionals.[64] Restricting conversations is highly unusual in health care, and especially end-of-life care, where having all available information is considered an essential component of person-centred decision making.[65] Willmott et al. argue this is likely to negatively impact anyone who is less educated, speaks a language other than English and/or who struggles with using a computer.[66]

Data shows access to VAD is generally lower in jurisdictions where conversations are restricted. In Victoria, for example, where initiating VAD conversations is strictly prohibited, VAD deaths as a proportion of all deaths are half those in Western Australia and Queensland,[67] where VAD can be raised alongside other options including palliative care. This difference has been noted by the independent Victorian VAD Review Board:[68]

> 'While it is not possible to be definitive about the reasons for this difference, the fact that health practitioners in [other jurisdictions] are not prohibited from initiating discussions about voluntary assisted dying … may explain a higher access rate in the initial implementation period than experienced in Victoria.'

Lengthy and complex processes

In all jurisdictions, the application and (prospective) approvals processes around VAD are time consuming and complex, both for patients and health professionals.[69] Finding practitioners able and willing to take VAD cases can be difficult, and small typographic or paperwork errors can hold up applications for days, sometimes weeks, potentially adding to patient suffering.

Across jurisdictions who have issued annual reports, between 30 and 50 per cent of people who commence the request and assessment process do not go on to complete it. While the reasons for this non-completion are varied (some people choose not to continue, others are deemed ineligible) these figures indicate the lengthy and complex application process and that a significant proportion of people begin their applications too late and die or lose capacity before they are able to complete it.

In Tasmania, where no online portal exists for VAD practitioners to facilitate applications, respondents to the *National VAD Survey* singled out the 'complex forms' and paper-based process as an area for urgent improvement.[70] Recognising this, the Tasmanian VAD Commission has recommended that the State Government purchase or develop an online portal similar to those used in mainland states for use by authorised medical practitioners.[71]

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[61] Vic VAD Review Board (2021-22b)
[62] ACT Government (2023)
[63] WA VAD Board (2022-23c)
[64] Waller K et al (2023)
[65] Waller K et al (2023); Willmott L, et al. (2020); McDougall, R et al. (2020)
[66] Willmott L et al. (2020)
[67] Vic VAD Review Board (2021-22); WA VAD Board (2022-23); QLD VAD Review Board (2022-23)
[68] Vic VAD Review Board (2022-23).
[69] White, B, et al. (2024b)
[70] Go Gentle Australia (2024b)
[71] TAS VAD commission (2022-23)

Time frames to death

All Australian states (and NZ) impose a 6-12 month time frame to death requirement in their legislation. Only Tasmania allows its VAD Commission to grant exemptions to these time frames in limited circumstances. The ACT takes a different approach and has removed this requirement altogether, recognising that an arbitrary time frame may act as an unnecessary barrier to access for otherwise eligible people.[72] The ACT approach shifts the emphasis back onto the nature of the illness, 'incurable, advanced and progressive, and is expected to cause death' and the suffering the person is experiencing, rather than gatekeeping access according to prognosis. It also avoids a health practitioner having to engage in the difficult and inexact science of predicting the timing of death.[73]

Eligibility criteria

Go Gentle frequently hears from people who express disappointment and disbelief[74] that eligibility criteria in Australia's VAD laws are so strict, resulting in people with grave illnesses remaining ineligible despite their significant suffering. Examples include Huntington's Disease, dementia and a range of chronic illnesses that do not easily lend themselves to prognostication.

Choice and control are of profound importance to Australians at the end of life. We anticipate the public discussion about eligibility criteria and VAD laws to continue and, most likely, intensify.

The 'gag clause': What doctors say[75]

You can talk about palliative care, but you're not allowed to tell them about the VAD option, which is a bit mad to me.

Dr Andrea Bendrups GP and Rheumatologist, Royal Melbourne Hospital

It affects the doctor-patient interaction and the doctor-nurse interaction. No-one is really sure whether every time the topic of VAD needs to be discussed, they have to wait for the patient to raise it first.

Dr Cam McLaren, Oncologist, Melbourne

It's like saying to someone with heart disease, I can give you pills but not tell them about the option of surgery. And voluntary assisted dying is one of their legal rights of medical care and for a doctor not to be able to inform someone of that is ridiculous.

Dr Nick Carr, GP Melbourne

People in rural and remote areas are often forgotten and have a difficult time accessing healthcare. With voluntary assisted dying there has been consideration for rural areas... QVAD SPS (Qld's VAD Support and Pharmacy Service) has been very good at bridging that gap.

Authorised VAD practitioner, QLD[76]

[72] White, B, et al. (2022)
[73] White, B & Willmott, L (2019)
[74] Go Gentle Australia (2024b)
[75] Go Gentle Australia (2024c)
[76] QLD VAD Review Board (2022-23b)

Commonwealth restrictions on electronic communications

The Criminal Code Act 1995 (Cth) prohibits the use of a carriage service to incite or encourage suicide. Health professionals risk breaking the law if they use telecommunications for many aspects of the VAD process.

VAD is not suicide, a fact made clear in the majority of VAD laws around the country. Australia's leading suicide prevention organisations (Black Dog Institute, Beyond Blue, Lifeline, Everymind) have signed a joint statement urging governments, commentators and the media to 'refrain from talking about VAD as suicide or using language that associates the two.'

> 'Suicide prevention and VAD should be discussed separately. Confusing these terms can delay access to suicide prevention services for people in distress, and complicate or delay care for people with terminal illness who are seeking an additional choice at the end of life.' [77]

The Federal Court, however, has contradicted this assessment, declaring that VAD is considered suicide for the purpose of the Criminal Code,[78] meaning VAD consultations must be done in-person. As a result, in some states, health professionals repeatedly make trips of 1000+kms to visit patients; nurses and care navigators are limited in what follow-up support they can offer by phone or email to patients and families; and scripts for VAD substances must be couriered or hand-delivered.

This adds significant delays and uncertainty for terminally ill people, their families and healthcare teams. QUT research in Victoria found the Code's prohibition on telehealth left people 'in tears and distressed and [in] hysterics'.

> 'Although this problem was often raised by people in regional areas, metropolitan participants were also concerned about requiring very unwell people to travel. The widespread use of telehealth during the coronavirus disease 2019 (COVID-19) pandemic compounded participants' sense of its prohibition being unjustified.' [79]

In 2023, the President of the Australian Medical Association (AMA), Dr Steve Robson, wrote to the Commonwealth Attorney-General to urge immediate reform:

> 'Doctors who participate [in VAD] must be protected and not liable to prosecution... [The telecommunications prohibition] also disadvantages patients who are physically unable to travel, even at relatively short distances, due to their medical condition.' [80]

In May 2024, state, territory and federal AMAs jointly called for the telecommunications restriction to be lifted.[81] In July 2024 a coalition of leading health organisations signed a joint statement (see Appendix 3) calling on the federal government to urgently ammend the Criminal Code where it negatively impacts provision of VAD services. This echoes calls by every state Health Minister[82], Attorney General[83] and statutory oversight body[84] as well as VAD practitioners nationwide who voted it the most pressing reform priority at the 2023 trans-Tasman VAD Conference.[85]

Residency requirements

All VAD laws specify that to be eligible for access a person must be a citizen or permanent resident of Australia, and ordinarily resident in the relevant state (for at least 12 months prior to their application). In lieu of citizenship or permanent residency, Tasmania, Queensland and NSW allow a person to be ordinarily resident in Australia for three continuous years immediately prior to making their first request.

Strict residency requirements are increasingly redundant as all jurisdictions pass and implement VAD laws. Their continued imposition acts as a serious barrier to access for otherwise eligible people.[86] Their removal should be a matter of priority or, failing this, provision for a compassionate exemption introduced so that there is a workable and sensible pathway for terminally ill people who need to relocate interstate (or from New Zealand) to be closer to family and support services. Limited versions of these exemptions have been included in VAD laws in Queensland, NSW and in the ACT.

[77] Joint statement from Australia's suicide prevention leaders (2023)
[78] Federal Court of Australia (2023)
[79] White B.P, et al. (2023)
[80] Australian Medical Association (2023)
[81] Australian Medical Association (2024)
[82] Correspondence to Go Gentle Australia (April 2024)
[83] Zimmerman, J, The West Australian (2023)
[84] Vic VAD Review Board (2021-22); etc
[85] Go Gentle Australia (2023)
[86] Bourke, K, ABC Stateline (2024)

Non-participation and obstruction

Although all Australian VAD laws allow an individual to choose not to participate in VAD, only four laws (South Australia, Queensland, NSW and the ACT) contain protections that prevent organisations and institutions obstructing an individual's choice.

Obstructing access to VAD can cause serious harm to dying people.[87] Finding a 'point of access' to VAD care has been identified as one of the biggest hurdles, especially when a person's own GP or treating physician declines to be involved.

Only in Western Australia and Queensland are practitioners who opt out of providing VAD care required to provide state government approved information on VAD so the patient can find assistance elsewhere. In Tasmania, there is a requirement that a medical practitioner provide the VAD Commission's contact details. In NSW, Victoria and South Australia, patient information resources are available for distribution and guidelines advise non-participating practitioners to refer the patient to the Care Navigation Service or an authorised VAD practitioner as appropriate[88]; however, conscientiously objecting practitioners are under no obligation to comply.

Regardless of what individual laws stipulate, health professionals should be aware of their respective codes of conduct regarding patient care, including guidance from the Medical Board of Australia, which make clear that practitioners should not use their conscientious objection to impede access to legal treatments or deny patients medical care.[89] This is echoed in Palliative Care Australia's 'guiding principles' for the provision of VAD in Australia.[90]

Although some jurisdictions do not spell out these expectations as they apply to institutions, the national regulator of aged care services, the Australian Aged Care Quality and Safety Commission, does: it says, unequivocally, that residents of aged care facilities have the right to choose to access VAD, even where the provider has decided not to participate.[91] Providers must respect an older person's choice; they have a responsibility to support access to VAD personnel; and no-one receiving aged care should be disadvantaged. Non-residential facilities such as hospitals and palliative care units similarly must not impede access to VAD personnel and, where appropriate, must arrange the transfer of the person to another facility to receive VAD care. These apply irrespective of whether or not the state's law obliges providers to facilitate VAD access.

The ACT is the first jurisdiction to impose financial penalties for individuals and institutions who block, harass, or attempt to coerce people from their legal VAD choice, or who obstruct the certification of a VAD death. These penalties, and a formal avenue to complain about obstruction and coercion, could be replicated in every jurisdiction to protect the rights of dying people.

Terminally ill people don't have time or energy to fight institutions

'I was really shocked to learn that a publicly funded hospital could have policies that existed on ideological or religious grounds,' says Miki, whose dying mother's Melbourne Catholic hospital refused to take part in her VAD application.

'Someone like my mum, who can't talk, can't move, can't advocate for themselves... is facing just about as many barriers as a person can face. So, every little hurdle that's added to that is just an enormous stress to overcome.

'Terminally ill people don't have time or energy to fight institutions. They need care and support. And they need to be enabled, and it needs to be as seamless and integrated as possible.'[92]

[87] White B.P, et al. (2023)
[88] NSW Health (2023)
[89] Australian Medical Council (2009)
[90] Palliative Care Australia (2022)
[91] Australian Government, Aged Care Quality and Safety Commission (2024)
[92] Annika Blau, ABC Background Briefing (2024)

Fair remuneration for health professionals

Many medical practitioners are poorly compensated for their time when supporting patients through VAD.[93] The Medical Benefits Schedule (MBS) has not been updated to reflect contemporary practice and still retains a general explanatory note that 'euthanasia and any service directly related to the procedure' will not attract Medicare benefits.[94] This fails to acknowledge the significant and time consuming role that health professionals play in VAD, and in particular the key role of GPs in VAD provision. As a result many doctors do not charge their patients for care they deliver, often leaving them unreimbursed for:

- support for family/carers
- the large volume of administrative work required, particularly for the coordinating practitioner
- services provided to public hospital inpatients
- non-GP private specialists providing services at a patient's home
- practitioner administration of the VAD substance
- travel time to a patient and accommodation costs (if required).

Expecting doctors to work pro bono – with many VAD cases requiring tens of hours of work – is not reasonable nor sustainable. Several state oversight bodies have highlighted that, if left unremedied, this is likely to diminish the pool of VAD practitioners and increase out-of-pocket costs for patients and their families.[95]

VAD must not become a care option only for those with the economic means. As Victoria's VAD Review Board has highlighted, 'some applicants have indicated that the financial burden associated with the process has impeded access or put pressure on finances for those supporting them through the process.' [96]

Jurisdictions are responding with their own funding solutions. A new practitioner funding package has been initiated in Western Australia and will be implemented in 2024-2025. NSW has put funding models in place with local health districts to resource central coordination and remuneration of VAD practitioners, including GPs engaged by the district. The current piecemeal funding available across jurisdictions is undesirable. Queensland's VAD Review Board has recommended a uniform approach to enable equitable remuneration to support a sustainable workforce.[97] MBS provision to allow GPs to claim against existing item numbers would go some way to address concerns, alongside state funding provision.

Australia should look to New Zealand, where comprehensive funding has been available to VAD practitioners since their law's inception.[98]

The National VAD Survey, July–Nov 2023[99]

91.3% of respondents 'agreed' or 'strongly agreed' that VAD should be a legal end-of-life care option

1 in 5 VAD applicants listed 'Access to trained and authorised medical practitioners' as a main challenge

82% of VAD practitioners agreed that 'Eligible people are generally satisfied with the care they receive'

2 in 3 VAD practitioners agreed that training prepared them for their role

50% of VAD practitioners disagreed with the statement 'I am appropriately remunerated for my role in the VAD program'

37% of VAD practitioners disagreed with the statement 'My organisation has the number and skill mix of practitioners to deliver a compassionate and person-centred service'

80% of non-VAD practitioners said they would consider doing VAD training in future.

[93] Haining, C. M, et al (2023); Go Gentle Australia (2024)
[94] Australian Government, Department of Health and Aged Care (2020)
[95] Vic VAD Review Board (2022-23); QLD VAD Review Board (2022-23); TAS VAD Commission (2022-23)
[96] Vic VAD Review Board 2022-2023b)
[97] QLD VAD Review Board (2022-23b)
[98] NZ Gazette (2021)
[99] Go Gentle Australia (2024b)

1.5 Compliance and safety

Compliance

Oversight bodies set up to monitor the operation of VAD laws are tasked with ensuring compliance with the law and maintaining public safety. Without exception, Australia's VAD laws are operating within the eligibility criteria and safeguards determined by parliament, with a compliance rate close to 100 per cent. Most instances of non-compliance have been to do with paperwork – none has involved eligibility.

There have been no referrals made to Police. One death (not of a VAD applicant) has been referred to a Coroner.

According to oversight bodies:

Victoria

In Victoria, since VAD became available, seven cases have been determined as non-compliant based on a delay with the return of the substance to the Statewide Pharmacy.

One case was found to be non-compliant with section 40(3)(b)(ii), which prohibits someone who signs a form on behalf of an applicant also being a witness to the document.

In another case of non-compliance, it was found that an assessing medical practitioner had not practised for at least five years after completing fellowship with a specialist medical college or vocational registration.

Four cases involving a single medical practitioner were deemed non-compliant because of an unintentional error in which a patient's first request was made to a medical practitioner who did not go on to become the coordinating medical practitioner. This is contrary to the requirements of the Act.

One case was deemed non-compliant due to a failure to comply with procedural requirements. This involved a final request form that had not been signed by a witness, and its re-lodgement which also did not meet necessary requirements. The Board referred the matter to the Australian Health Practitioner Regulation Agency (AHPRA), which admonished the medical practitioner. The practitioner was subsequently fined $12,000.

Tasmania

In Tasmania, the VAD Commission has received no notifications of contraventions of the Act.

Queensland

In Queensland, in the first six months of operation of VAD, the Review Board did not refer any issues regarding non-compliance to any of the referral entities specified in the Act. The Board was aware of one incident involving VAD substance misuse that had separately been referred to the Coroner.

Western Australia

In Western Australia, the Voluntary Assisted Dying Board has made four referrals to the Chief Executive Officer of the Department of Health relating to the timeliness of an authorised disposal of a voluntary assisted dying substance.

South Australia

In South Australia, no issues have been identified requiring referral to Police; the Registrar; the Chief Executive; the State Coroner; or the Australian Health Practitioner Regulation Agency (AHPRA).

Safety

Only Western Australia publishes data relating to substance administration experiences and complication rates. This is for practitioner administration only. (No data is collected for private self-administrations.)

The WA VAD Board states:[100]

> 'At the time of administration, practitioners are required to notify the Board of any complications that occur during the administration. In 2022–23, 94.3 per cent of deaths following practitioner administration (n=198) were reported without complication, which has decreased from 97.3 per cent in 2021–22 (n=144). There were 13 complications reported in 2022–23 (5.7% of deaths), with one patient episode recording more than one complication.
>
> Intravenous line complications were recorded as the most common complication (n=7), followed by other (n=5) and worsening of pain or discomfort (n=1). Complications reported as other included coughing, burning of the throat following assisted oral ingestion, transient agitation and pain following injection following intravenous administration. All patients with reported complications died after administration of the voluntary assisted dying substance.

[100] WA VAD Board (2022-23)

> The Board completed case reviews of all reported complications.'

In its 2022-23 Annual Report, the Victorian VAD Review Board noted in its compliance reviews summary that it had reviewed cases where the time to death following enteral or oral administration of the substance 'has been prolonged'.[101]

> 'The majority of these have been applicants diagnosed with a neurodegenerative disease that causes autonomic nervous system failure in addition to a progressive movement disorder. For these applicants, gastric emptying will have been slow and gut motility reduced and this may have been a contributing factor to the prolonged time to death.
>
> The Board advises that medical practitioners should consider discussing with an applicant this potential impact when considering the permit application. Practitioner administration could be considered for applicants with these diagnoses.'

In the interest of transparency, public confidence and service improvement, it would be helpful if all jurisdictions collected and published this data.

Length of time to death of patient via intravenous administration in 2021 to 2023

(taken from the WA VAD Board annual report 2022-23)

P5 Length of time to death	2021-22	2022-23	Total	% of total
≤ 15 minutes	90	155	245	93.5%
≥ 16 minutes	6	11	17	6.5%
Total	**96**	**166**	**262**	**100%**

In 2022-23, after practitioner intravenous administration:

- the median time to death was 5 minutes, a decrease from 8 minutes in 2021-22
- 93.4 per cent of patients died within 15 minutes
- time elapsed between substance administration and death ranged from 1 minute to 30 minutes

Length of time to death of patient via assisted oral ingestion, assisted ingestion via PEG or NG tube in 2021 to 2023

(taken from the WA VAD Board annual report 2022-23)

P5 Length of time to death	2021-22	2022-23	Total	% of total
≤ 29 minutes	42	30	72	75.0%
30 to 60 minutes	6	9	15	15.6%
≥ 61 minutes	4	5	9	9.4%
Total	**52**	**44**	**96**	**100%**

In 2022-23, after practitioner assisted oral ingestion or assisted ingestion via PEG or NG tube:

- the median time to death was 19 minutes, an increase from 15 minutes in 2021-22
- 88.6 per cent of patients died within 60 minutes
- time elapsed between substance administration and death ranged from 7 minutes to 6 hours and 29 minutes

[101] Vic VAD Review Board (2022-23e)

2. Aotearoa New Zealand

2.1 The NZ model

The End of Life Choice Act 2019 governs assisted dying provision in Aotearoa New Zealand. It is similar to Australia's model in that medical assistance to die is limited to terminally ill adults of sound mind who are suffering intolerably. The legislation received 65 per cent public support in a referendum prior to its enactment.

Eligibility

Aotearoa New Zealand's (NZ) model of assisted dying shares the majority of its eligibility criteria and process with the 'Australian model' of VAD. Applicants must be adults, with decision-making capacity and permanent residency or citizenship. As in Victoria and South Australia, the NZ law prohibits health professionals from raising assisted dying with their patients.

However, there are some key differences between the NZ and Australian models:

1. To be eligible, a person must be suffering from a terminal illness that is likely to end their life within six months, there is no separate 12-month provision for neurodegenerative diseases
2. Training for assisted dying practitioners is not mandatory; however, everyone must adhere to the processes as set out in the law
3. Practitioners who do complete the Health Ministry's training can claim remuneration for their work
4. Telemedicine can be used in assisted dying practice, in line with professional standards. First assessments must be in-person
5. People can choose between self and practitioner administration. They are issued a permit for both once deemed eligible, promoting flexibility and choice
6. People can choose the location of their assisted death. Close to 80% achieve a death at home
7. Intravenous self-administration of the VAD substance is allowed (although rarely chosen), providing access and control for dying people unable to ingest the substance another way.

Mate whakaahuru is the te reo Māori translation of 'assisted dying'. It means 'to die in a warm and comforting manner' [102]

[102] NZ Assisted Dying Service Ngā Ratonga Mate Whakaahuru (2022)

NZ Snapshot

Data sourced from the Registrar (AD)'s Annual Reports and from the Ministry's quarterly reporting. Data correct to March 2024[103]

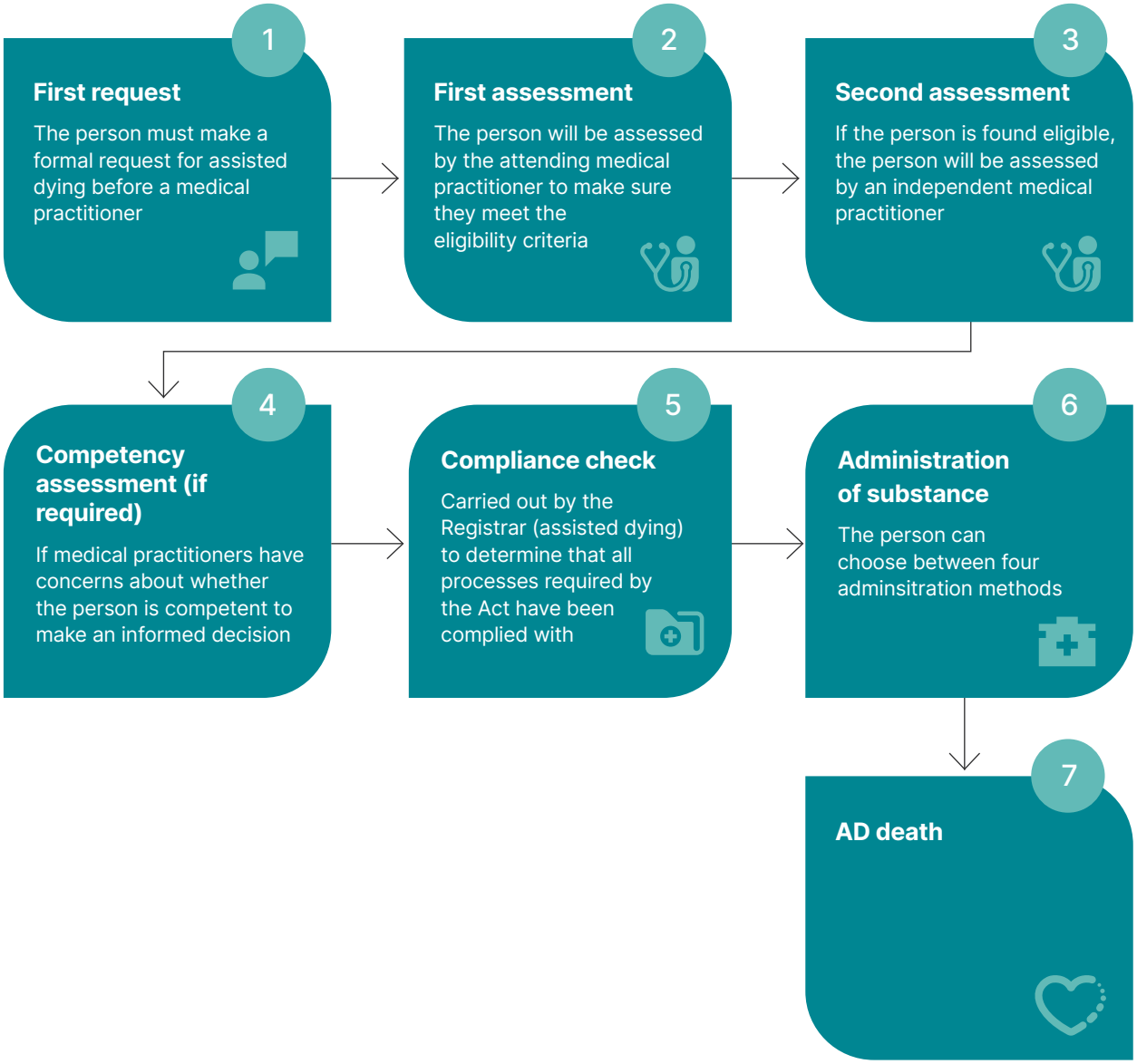
No of applicants	1870
No of VAD deaths	775
% of applicants aged 65+	76.9
Gender Male (%)	48.3
No of VAD-qualified health professionals	137*
% of applicants with cancer	68.5
Average time between initial formal application and eligibility approval[104]	18 days**
Receiving palliative care %	76.1***

* Medical practitioners, psychiatrists and nurse practitioners who appear on the SCENZ list. Not all AD practitioners appear on this list. Correct at March 2024

** Data available for 2023 only

*** at the time of application

AD process



[103] NZ Assisted Dying Service (2021-22); NZ Assisted Dying Service (2022-23); NZ Assisted Dying Service (2024); NZ Assisted Dying Service Ngā Ratonga Mate Whakaahuru (2022)
[104] NZ Assisted Dying Service Ngā Ratonga Mate Whakaahuru (2023)

2.2 Who is using Assisted Dying?

Assisted dying (AD) has been an option for eligible people in New Zealand since November 2021. Available data shows there have been 1,870 applications and 775 assisted deaths.[105]

Most commonly, AD applicants in New Zealand are women aged 65+ with a cancer-related diagnosis.

The vast majority of assisted deaths (80.8%) were Pākehā or people of NZ European background (Pākehā represent around 68 per cent of the general population); 14 per cent were people who identified as 'other' ethnicity; 4.3 per cent were Māori (18% of the national population); 2 per cent Asian (17% of the national population); and 0.4 per cent identified as Pacifica New Zealanders (9% of the national population).[106, 107]

A small fraction of total deaths

Since 2021, the number of AD deaths has represented a small fraction of all deaths, accounting for around 1 per cent of total deaths.[108]

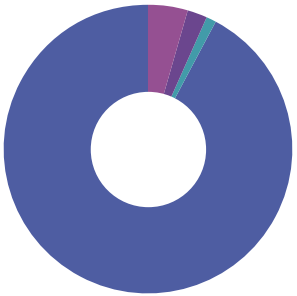
Intersection with palliative care and end-of-life care

76% of people were receiving or had received palliative care at the time of their AD application.

Method of administration

Under the NZ Act, a person is offered four options for the administration of the assisted dying substance. Unlike Australia, IV self-administration is permitted (although rare). The Registrar's 2023 annual report shows an overwhelming majority (9 out of ten people) chose intravenous delivery triggered by a health professional.

Method of administration NZ
1 April 2022 to 31 March 2023[109]

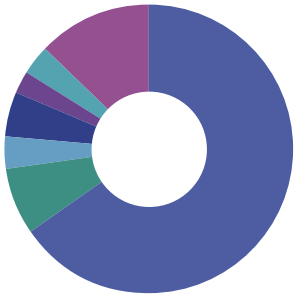


Method	%
Ingestion triggered by person	4.6
IV triggered by person	2.1
Ingestion via a feeding tube, triggered by a health professional	1.2
IV triggered by a health professional	92.1

Reasons for seeking AD

Since AD became available in November 2021, cancer-related diagnoses have consistently been the most common among AD applicants (68.5%).

Diagnosis category
November 2021 to March 2024



Diagnosis	%*
Cancer	68.5
Neurological condition	7.6
Chronic respiratory disease	4
Cardiovascular condition	5
Other organ failures	2.6
Other diagnosis	3.6
Not known	13.2**

* Individuals presenting with multiple diagnoses are included within each applicable diagnostic category, and the total may not add up to 100.

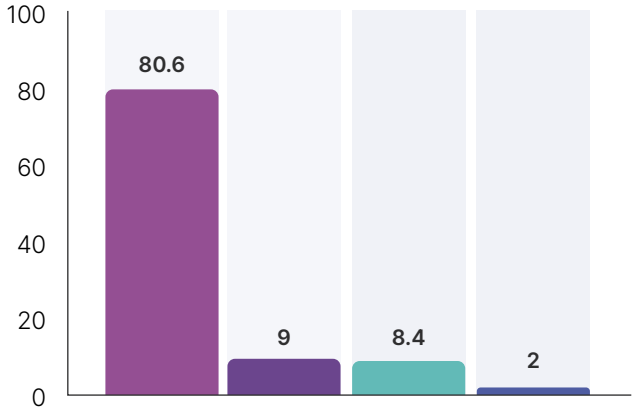
** 'Diagnosis not known' includes individuals who have applied but have not yet completed their first assessment, as well as those who have withdrawn before assessment, died before this assessment was completed, or were ineligible due to not having a terminal illness[110]

[105] NZ Assisted Dying Service (2021-22); NZ Assisted Dying Service (2022-23); NZ Assisted Dying Service (2024)
[106] ibid
[107] Stats NZ (2024a)
[108] Stats NZ (2024a)
[109] NZ Assisted Dying Service Ngā Ratonga Mate Whakaahuru (2023b)
[110] ibid

Place of death

Eight in ten (80.6%) New Zealanders who accessed an assisted death died at home. This compares with ~49% in Australia. Of the remainder, 9 per cent died in aged care, 8.4 per cent in hospital and 2 per cent in a hospice or another type of community care facility. Only one hospice, Tōtara Hospice, allows AD to take place on site.

Place of assisted death[111]



Place of AD	%
Home (or other private property)	80.6
Aged Care Facility	9
Hospital	8.4
Hospice (or other community facility)	2

2.3 Who is providing AD care?

New Zealand's AD oversight body has said that, after the first year, the number of medical and nurse practitioners willing to provide AD services was sufficient to meet demand and had remained stable since the service became available.[112] Areas with low numbers of trained practitioners are served by health professionals who are willing to travel to provide services and to use telehealth consultations, where appropriate.

AD practitioners are from a range of backgrounds. The Registrar's figures from 2022 show 40 per cent were specialist doctors, 40 per cent were working in general practice, 20 per cent other (no specialist scope).[113] The majority of these (n=137 in March 2024) are on the approved SCENZ lists (the statutory body for the AD service), but there is no exact number of AD practitioners.

Health workforce training

Training is available for medical and nurse practitioners who will be involved in AD, but also for the wider health workforce so even those not actively involved in AD care know their rights and responsibilities under the Act. The Registrar's 2023 report shows that as of March 2023, 18,314 health professionals had completed training to learn about the End of Life Choice Act, the assisted dying pathway and how to respond if someone raises AD.[114]

AD practitioner background

Background	%
Specialist doctors	40
Working in general practice	40
Other (no specialist scope)	20

Health practitioner remuneration

A significant strength of the AD service in NZ is the funding provision, which covers the number of hours required to care for patients but also travel time and expenses related to seeing patients wherever they are in the country. It promotes equitable access for patients and looks after the workforce to ensure sustainability of the AD service.[115]

[111] NZ Assisted Dying Service (2021-22); NZ Assisted Dying Service (2022-23); NZ Assisted Dying Service (2024)
[112] NZ Assisted Dying Service Ngā Ratonga Mate Whakaahuru (2022)
[113] ibid
[114] NZ Assisted Dying Service Ngā Ratonga Mate Whakaahuru (2023)
[115] NZ Gazette (2021)

2.4 Barriers to access & equity

In November 2024, the End of Life Choice Act will undergo its three-year legislative review. Supporters of the law[116] are calling for change in four key areas:

1. **The 'gag clause': Health practitioners cannot initiate discussions about assisted dying with patients**
   This clause can limit equitable care, as many people do not know assisted dying is an option. This is likely to disproportionately impact vulnerable and low socioeconomic population groups. The health literacy of patients should not determine their access to a standard health service and choice. In the majority of Australian states health professionals can raise VAD with their patients so long as they also discuss the other available end-of-life options, including palliative care.

2. **Time frame to death: You must have six months or less to live to apply**
   The short time frame to death for all conditions can block access for people who have illnesses that are difficult to prognosticate or neurodegenerative conditions, such as motor neurone disease, because they lose the ability to communicate and/or capacity earlier in their disease's progression.[117] All Australian laws allow people with a neurodegenerative illness to apply within 12 months of expected death; Queensland allows anyone to apply with 12 months of life left, regardless of the illness; and the ACT law has removed time frames altogether. This is person-centred as the process recognises people with neurodegenerative conditions face unique challenges and suffering and can take time to navigate and organise their care.

3. **Institutional 'conscientious' objection**
   While individual conscientious objection is permitted in the law, the Act is silent on institutional non-participation. While the majority of hospices now allow assessment for eligibility of assisted dying to take place on site, a number of people seeking AD have been obstructed by hospitals and hospices who do not allow AD on their premises.[118] Although the notion that institutions can possess a 'conscience' is contested, the view that hospices may object to providing AD has received qualified support in NZ's High Court.[119] More needs to be done to ensure institutions know their obligations to the people in their care and do not obstruct people from their legal choice.

4. **The '48-hour rule'**
   For an assisted death to be expedited for clinical reasons, a minimum of two working days is required for Registrar approval. This adds unnecessary red tape and delays and is a barrier to timely and appropriate care.

2.5 Safety and compliance

Data shows the Assisted Dying Service is running safely and as intended. The End of Life Choice Act established a number of bodies and roles to ensure the safe operation of assisted dying in NZ, including the Registrar (Assisted Dying). The Registrar performs a regulatory and monitoring function similar to that of the VAD Review Boards in Australia; reviewing assisted dying forms completed by practitioners to ensure compliance prior to prescriptions being released; managing complaints; and publishing an annual report for the health minister.

Te Whatu Ora (the publicly funded health care system) is now responsible for service activity reporting, which it releases on a quarterly basis.

There have been no major complications with the administration of the assisted dying substance and all deaths have occurred within expected time frames. No complaints regarding AD have been referred to the New Zealand Police or the Nursing Council.

A number of complaints have been referred to the Health and Disability Commissioner and are currently under investigation. One relates to conduct in an aged care facility and three relate to the conduct of a health professional. None has yet resulted in a finding against a health professional or institution.[120]

[116] Supporter statements from Dr Laura Chapman, NZ representative, VADANZ Steering Committee (2024); End of Life Choice Society NZ; David Seymour MP via Moir, J, RNZ (2024)
[117] Open letter to NZ Herald (2023)
[118] Wenley, S, RNZ (2023)
[119] Hurley S, NZ Herald (17 June 2020)
[120] NZ Assisted Dying Service Ngā Ratonga Mate Whakaahuru (2023)

State of VAD - Conclusions

When discussing the findings from this report we must acknowledge that they are based on an imperfect data set, with many instances of similar but not identical data being collected by different jurisdictions. Further work is needed to standardise and align data sets to allow deeper insights into the way VAD is operating across Australia and NZ and to support a growing body of research.

The overarching conclusion from the available data is that Australian and New Zealand models of assisted dying are meeting their goal to provide a safe and compassionate legislative framework for terminally ill people to access medical assistance to die.

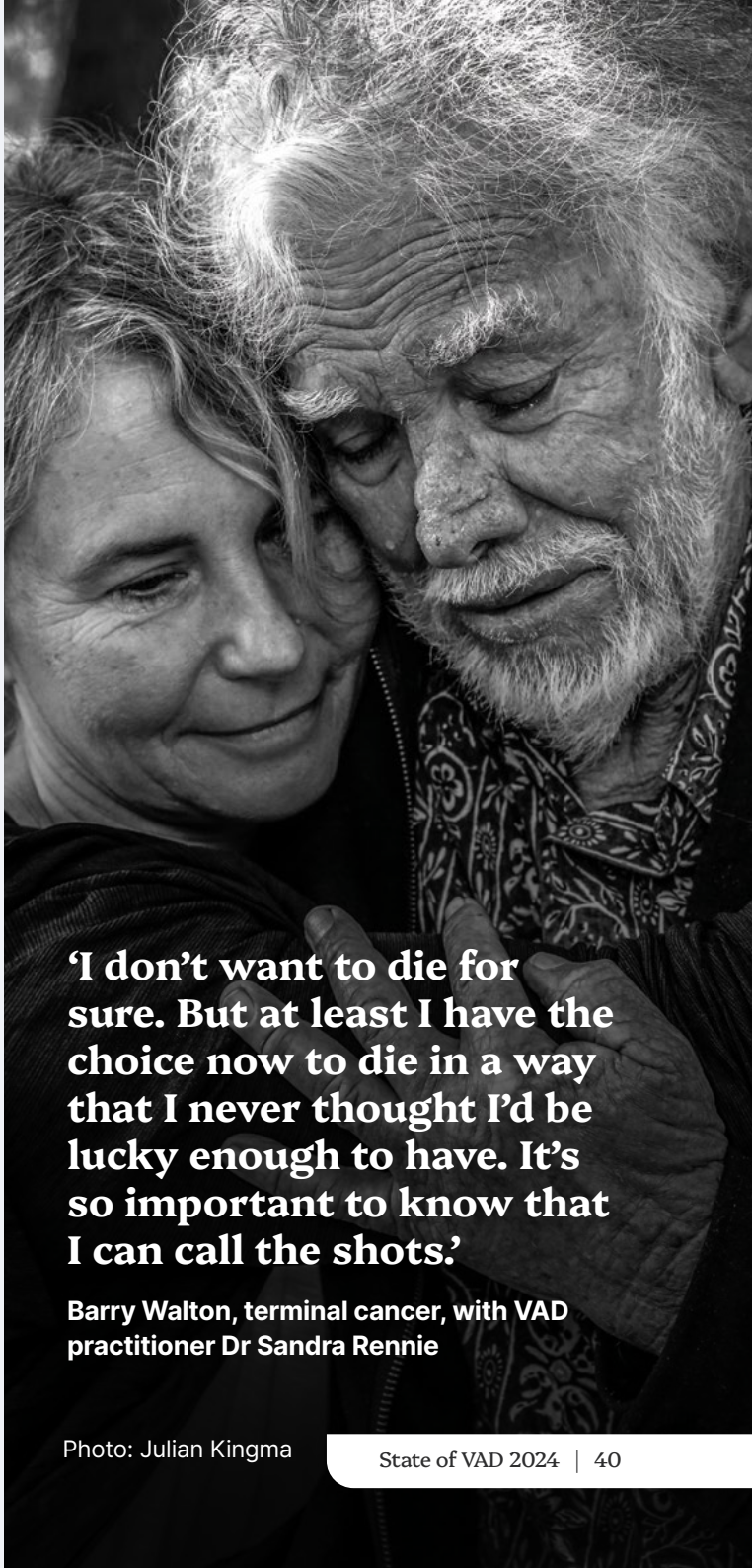
However, some provisions, intended as safeguards, are operating as barriers to access for eligible people. This report highlights these, and recommends barriers be removed to ensure access to, and the sustainability of, VAD provision.

At the operational level, a priority must be to engage more health professionals in VAD services. In Australia, measures to ensure fair remuneration, acceptable workloads, and organisation-level training and support would go a long way to facilitate this. The emergence of VADANZ, a multidisciplinary peak body to represent VAD health professionals, will ensure these issues are not overlooked.

For the eligible terminally ill people who seek the VAD choice, more needs to be done to facilitate access in regional and remote areas. Increased funding for rural and regional access schemes and reform of the Commonwealth Criminal Code in Australia to allow the use of electronic communications and telehealth in VAD, where clinically appropriate, would be significant steps forward. So too would be the removal of the unprecedented 'gag clause' preventing medical professionals from initiating conversations about VAD in Victoria, South Australia and New Zealand. More attention also must be given to the creation of culturally safe information and resources for First Nations Australians and New Zealanders and migrant communities.

Many of these reforms can be initiated via guidelines, regulations and financial commitment. Some may need to wait for statutory reviews scheduled in all jurisdictions. We urge governments not to unnecessarily delay reform.

The ACT's VAD law, which passed on 5 June 2024, is a significant development. This legislation, formulated after extensive community and health sector consultation, is the most person-centric of laws, removing the time frame to death, giving experienced nurses a greater role and spelling out the obligations institutions have to the people in their care, including penalties for obstructing access. It continues the evolution of the 'Australasian model' of VAD and other jurisdictions will be closely watching the ACT's implementation and rollout of VAD services.



'I don't want to die for sure. But at least I have the choice now to die in a way that I never thought I'd be lucky enough to have. It's so important to know that I can call the shots.'

Barry Walton, terminal cancer, with VAD practitioner Dr Sandra Rennie

Photo: Julian Kingma

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Appendix 1

Comparison table: Australian & NZ Assisted Dying laws

This table intends to provide an overview only | Click the name of each jurisdiction to access their legislation | Jurisdictions appear in the order their laws passed
Last updated: June 2024

Date of commencement	19/06/2019	01/07/2021	07/11/2021	23/10/2022	01/03/2023	01/01/2023	28/11/2023	03/11/2025
Length of Act (pages)	134	115	29	67	67	113	84	132
Eligibility	**VIC**	**WA**	**NZ**	**TAS**	**SA**	**QLD**	**NSW**	**ACT**
Aged 18+	✓	✓	✓	✓	✓	✓	✓	✓ (adult)
Resident in jurisdiction	✓ (12 m)	✓ (12 m)	✓	✓ (12 m)	✓ (12 m)	✓ (12 m or granted exemption)	✓ (12 m or granted exemption)	✓ (12 m or granted exemption)
Citizen or permanent resident only	✓	✓	✓	✓ (or 3 yrs Aus residency)	✓	✓ (or 3 yrs Aus residency)	✓ (or 3 yrs Aus residency)	
Person has decision-making capacity in relation to assisted dying	✓	✓	✓	✓	✓	✓	✓	✓
Person is acting voluntarily and without coercion	✓	✓	✓	✓	✓	✓	✓	✓
Diagnosed with an eligible disease, illness or medical condition (eg, advanced, incurable, progressive, will cause death)	✓	✓	✓	✓ (or injury)	✓	✓	✓	✓
Disease expected to cause death within a specified timeframe	✓ (6 m, 12m for neuro)	✓ (6 m, 12m for neuro)	✓ (6 m)	✓ (6 m, 12 m for neuro, or granted exemption)	✓ (6 m, 12m for neuro)	✓ (12 m)	✓ (6 m, 12m for neuro)	person must be approaching the end of their life
Person is suffering	✓	✓	✓	✓	✓	✓	✓	✓
Express provision that mental illness or disability alone is not an eligible disease, illness or medical condition	✓	✓	✓	✓ ('injury' and some physical disabilities may be eligible)	✓	✓	✓ (also discounts dementia)	✓ (some physical disabilities may be eligible)
Review by tribunal of some eligibility criteria (eg residency, decision making capacity or voluntariness, or relevant medical condition (prognosis))	✓ (VCAT)	✓ (SAT)	Complaints to Secretariat or Health & Disability Commissioner	✓ (by VAD Commission)	✓ (SACAT)	✓ (QCAT)	✓ (NSW Supreme Court)	✓ (ACAT)

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VAD request process	VIC	WA	NZ	TAS	SA	QLD	NSW	ACT
Health practitioner prohibited from raising VAD with patients, even in the context of all a person's care and treatment choices (the 'gag clause')	✓		✓		✓			
Person must make request themselves	✓	✓	✓	✓	✓	✓	✓	✓
Person can request VAD in advance (e.g. advance directive)								
Person must make three separate requests	✓	✓	✓	✓	✓	✓	✓	✓
One request must be written, in presence of two witnesses	✓	✓	Person must sign a form in their VAD Dr's presence	✓ (or a Commissioner for declarations)	✓	✓	✓	✓
Required waiting period between first and final requests	✓ (9 days unless likely to die)	✓ (9 days unless likely to die or lose capacity)		✓ (4 days unless likely to die or lose capacity)	✓ (9 days unless likely to die)	✓ (9 days unless likely to die or lose capacity)	✓ (5 days unless likely to die or lose capacity)	
Interpreters must meet certain standards (e.g. independence)	✓	✓		✓	✓	✓	✓	✓
Person may pause or withdraw their request any time	✓	✓	✓	✓	✓	✓	✓	✓
VAD assessment process	**VIC**	**WA**	**NZ**	**TAS**	**SA**	**QLD**	**NSW**	**ACT**
Person must be assessed as eligible by two appropriately qualified doctors	✓	✓	✓	✓	✓	✓	✓	✓ (experienced nurse practitioners can perform one assessment, provided the other is by a Dr)
Referral to another medical practitioner if eligibility cannot be determined (eg there is uncertainty about the person's diagnosis or decision-making capacity)	✓	✓	✓	✓	✓	✓	✓	✓
Person must be given particular information (eg about their diagnosis, options and the taking of the substance)	✓	✓	✓	✓	✓	✓	✓	✓
Telemedicine may be used where clinically appropriate	prohibited by Cth Criminal Code	prohibited by Cth Criminal Code (but law permits telehealth in some circumstances)	✓	prohibited by Cth Criminal Code (but law permits telehealth in some circumstances)	prohibited by Cth Criminal Code (guidance permits telehealth in some circumstances)	prohibited by Cth Criminal Code	prohibited by Cth Criminal Code	prohibited by Cth Criminal Code

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Accessing the VAD substance	VIC	WA	NZ	TAS	SA	QLD	NSW	ACT
Self-administration is default	✓ (practitioner administration available only if patient incapable of self-admin)	✓ (practitioner administration available if patient incapable or has concerns RE self-admin)			✓ (practitioner administration available only if patient incapable of self-admin)	✓ (practitioner administration available if self-admin inappropriate)		
Person has a choice between self or practitioner administration			✓	✓ (although final decision made my practitioner)			✓	✓
Practitioners allowed to administer	Doctors	Doctors, Nurse Practitioners	Doctors, Nurse Practitioners	Doctors, Nurse Practitioners, Registered Nurses	Doctors	Doctors, Nurse Practitioners, Registered Nurses	Doctors, Nurse Practitioners	Doctors, Nurse Practitioners, Registered Nurses
Practitioner administration must be witnessed	✓	✓			✓	✓	✓	✓
A contact person must be appointed	✓	✓ (self-admin)		✓ (private self-admin)	✓	✓	✓ (self-admin)	✓ (self-admin)
Additional approval process — permit required to prescribe and supply, or possess and administer, voluntary assisted dying substance	✓			✓	✓		✓	
Provisions governing the management of the voluntary assisted dying substance eg, must be prescribed in accordance with requirements	✓	✓	✓	✓	✓	✓	✓	✓
Role of health practitioners	**VIC**	**WA**	**NZ**	**TAS**	**SA**	**QLD**	**NSW**	**ACT**
Can choose not to participate (eg conscientious objection)	✓	✓	✓	✓	✓	✓	✓	✓
If not participating, must provide information to access VAD (duty to 'refer on' or provide info about jurisdiction's services)		✓	✓	✓		✓		✓
Must meet minimum levels of qualification and experience	✓	✓	✓	✓	✓	✓	✓	✓
Must complete mandatory training before assessing person	✓	✓	✓ (if they are to be paid by the government)	✓	✓	✓	✓	✓
Mandated reporting throughout the VAD process	✓	✓	✓	✓	✓	✓	✓	✓

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Entity participation	VIC	WA	NZ	TAS	SA	QLD	NSW	ACT
"Facility" includes hospitals/non-residential health care, as well as retirement villages and residential health care	legislation is silent on entity participation	legislation is silent on entity participation	legislation is silent on entity participation	legislation is silent on entity participation	✓	✓	✓	✓
Facility must not hinder person's access to information about VAD					✓	✓	✓	✓
Facility must allow residents reasonable access to VAD or facilitate transfer for assessments					✓	✓	✓	✓
Residents and non-residents receive the same protections								✓
Facility may object to allowing assessments for non-residents (unless unreasonable, causing harm or financial loss to patient, in which case access must be allowed or transfer facilitated)					✓(hospitals not required to allow access but must transfer)	✓	✓ (hospitals not required to allow access but must transfer)	✓ (protections apply equally to residents and non-residents)
Facility must allow residents administration of VAD substance					✓	✓	✓	✓
Facility may object to allowing administration of substance for non-residents (unless unreasonable, causing harm or financial loss to patient, in which case access must be allowed or transfer facilitated)					✓ (hospitals not required to allow access but must transfer)	✓	✓(hospitals not required to allow administration but must transfer)	residents and non-residents receive same protection
Facility must inform public of non-availability of VAD					✓	✓	✓	✓

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Legal offences and protections	VIC	WA	NZ	TAS	SA	QLD	NSW	ACT
Legislation explicitly says that VAD is not suicide		✓		✓	✓	✓	✓	✓
Protections for health practitioners abiding by their jurisdiction's VAD law and acting in good faith	✓	✓	✓	✓	✓	✓	✓	✓
Offence to induce a person to request VAD	✓	✓	✓ (offence to wilfully fail to comply with any element of the Act)	✓	✓	✓	✓	✓ (make or revoke a VAD request)
Offence to induce a person to self-administer	✓	✓		✓	✓	✓	✓	✓
Offence to falsify records, or make a false or misleading statement	✓	✓		✓	✓	✓	✓	
Offence to fail to report on assisted dying	✓	✓		✓	✓	✓	✓	✓ (technical error does not invalidate process)
Offence to administer the substance when not authorised to do so	✓	✓		✓	✓	✓	✓	✓
Offence for contact person to fail to return unused VAD substance	✓	✓		✓	✓	✓	✓	✓
Oversight	**VIC**	**WA**	**NZ**	**TAS**	**SA**	**QLD**	**NSW**	**ACT**
Oversight by an independent body	✓ (Review Board)	✓ (Review Board)	✓ (Registrar)	✓ (Commission)	✓ (Review Board)	✓ (Review Board)	✓ (Review Board)	✓ (Oversight Board)
Review of legislation	4 years (review due 2024)	2 years (review due 2024, then max 5 yearly)	3 years (review due 2025, then max 5 yearly)	3 years (review due 2025, then max 5 yearly)	After 4 years and before 5 years (by Jan 2028)	3 years (review due 2026)	2 years (review due 2025/6, then max 5 yearly)	3 years (review due 2028/29, then 5 yearly)

Appendix 2

Joint statement by Australia's suicide prevention leaders

VOLUNTARY ASSISTED DYING SHOULD NOT BE DESCRIBED AS SUICIDE

As organisations working in suicide prevention and mental health, we acknowledge that both suicide and voluntary assisted dying (VAD) are important to our communities and warrant discussion.

But the words we choose when doing this matter.

In our view, public discussion about suicide and suicide prevention differs from the conversation about VAD. The organisations that provide information and support for each of these issues are also distinct.

Suicide prevention and VAD should be discussed separately. Confusing these terms can delay access to suicide prevention services for people in distress, and complicate or delay care for people with terminal illness who are seeking an additional choice at the end of life.

In any public communication, it is important that we refrain from talking about VAD as suicide or using language that associates the two.

We ask all governments, people working in suicide prevention, commentators and the media to uphold this distinction in the language we use about VAD to ensure our communities get the right information and support.

We encourage anyone who is commenting on the topic of suicide to be familiar with the Mindframe guidelines

** A shorter version of this statement can be found here*

Lifeline · EVERYMIND · Black Dog Institute · Beyond Blue

November 2023

Explanatory note

We are concerned that suicide is being confused with voluntary assisted dying. The two are very distinct, and using the terms interchangeably can be damaging.

Suicide is when a person tragically and intentionally ends their own life. There are complex reasons why someone might think about ending their life and this is not always preceded by a single event or condition.

Suicide can be prevented with the right support and care, including the crisis support and counselling services that our organisations provide.

Voluntary assisted dying is not a choice between life and death. It is an end-of-life choice available to eligible terminally ill people who are already dying. It offers an element of control and comfort over how they die when death becomes inevitable and imminent. Voluntary assisted dying is coordinated with the support of health professionals and guided by clinical protocols.

Both suicide prevention and voluntary assisted dying are as important as they are distinct. Confusing these terms can delay access to suicide prevention services for people in distress, and complicate care for those who are at end of life.

Words matter

Refrain from using terms such as assisted suicide, medically assisted suicide or physician assisted suicide.

In Australia, the agreed term is 'voluntary assisted dying' which accurately describes the options available to terminally ill people under Australia's laws. Voluntary assisted dying is:

- **VOLUNTARY:** the decision to seek life ending medication must be voluntarily and made without pressure or coercion.
- **ASSISTED:** by health practitioners. If a person is considered eligible and is determined to proceed, they either self-administer a substance prescribed by a doctor or have an experienced doctor or nurse administer the substance for them.
- **DYING:** to be eligible the person must be terminally ill, suffering and at the very end of their life.

Examples of problematic language & alternatives

Not: *Terminally ill people are able to access medically assisted suicide if doctors say they have fewer than 12 months to live.*

Instead: *Terminally ill people are able to access **voluntary assisted dying** if doctors say they have fewer than 12 months to live.*

Not: *When assisting someone to suicide using the prescribed medication, doctors must follow strict protocols.*

Instead: *When helping someone to access the prescribed medication for **voluntary assisted dying**, doctors must follow strict protocols.*

A process facilitated by Go Gentle Australia

Appendix 3

Joint statement: Electronic communications must be available for voluntary assisted dying

We call on the government to urgently amend the Commonwealth Criminal Code where it negatively impacts provision of voluntary assisted dying services.

Pharmaceutical Society of Australia
AMA QUEENSLAND
CHF
ahha
Australian Nursing & Midwifery Federation
Pharmaceutical Society of Australia
Australian Medical Association QLD
Consumers Health Forum of Australia
Australian Healthcare and Hospitals Association
Australian Nursing & Midwifery Federation
PeterMac
shpa
Clinical Oncology Society of Australia
OPAN
acnp australian college of nurse practitioners
apna
Peter MacCallum Cancer Centre
Society of Hospital Pharmacists Australia
Clinical Oncology Society of Australia
Older Persons Advocacy Network
Australian College of Nurse Practitioners
Australian Primary Health Care Nurses Association
Australian Lawyers Alliance
HealthCare Consumers
AASW Australian Association of Social Workers
amsa
AAPi Australian Association of Psychologists Inc
VADANZ
Public Health Association
Australian Lawyers Alliance
Health Care Consumers
Australian Association of Social Workers
Australian Medical Students' Association
Australian Association of Psychologists
Voluntary Assisted Dying Australia & NZ
Public Health Association

Electronic communication is essential for high-quality and safe health care. However, the Cth Criminal Code's restriction on how health professionals communicate about voluntary assisted dying (VAD) is causing disruptions and delays in care, and limiting health professionals' ability to do their jobs.

The prohibition of electronic communication for VAD care disadvantages people who are unable to travel for face-to-face consultations due to the complexity of their medical condition or because they live in a rural or remote area. Essential communications between health professionals are also negatively impacted.

The use of electronic communications in health care, such as telehealth and video conference, is governed by specific guidance from the Australian Health Practitioner Regulation Agency (Ahpra) and the Medical Board of Australia. Health professionals must also follow their professional bodies' Code of Conduct at all times, irrespective of the type of care (e.g. Codes from Medical Board of Australia, Ahpra's Shared Code of Conduct and the Nursing and Midwifery Board's Code).

It should be for health professionals and their patients to decide if electronic communications are an appropriate alternative to in-person care. In May 2024, state, territory and federal branches of the Australian Medical Association (AMA) wrote to the Australian government to urge reform.

The Cth Criminal Code provisions were never intended to impact VAD. All state laws, except Victoria, explicitly distinguish VAD from suicide. Australian suicide prevention organisations agree that VAD should not be described as suicide because conflating the two can be damaging. Criminal Code provisions should not apply.

Background

In 2005, the Criminal Code Act 1995 (Cth) was amended to, in the words of the then-Attorney General, 'protect vulnerable individuals from people who use the internet with destructive intent to counsel or incite others to take their own lives'. The intent was to restrict pro-suicide chatrooms and materials being distributed online.

Sections 474.29A and 474.29B of the Commonwealth Criminal Code (contained in Schedule 1 of the Act) made it an offence to use a 'carriage service' to publish or distribute material that counsels or incites a person to suicide.

Unfortunately, state voluntary assisted dying (VAD) laws are caught up in the same prohibition - despite leading suicide prevention organisations releasing a joint statement distinguishing VAD and suicide, and all state VAD laws (except Victoria) explicitly stating the same.

In practice, the prohibition means no conversations about the delivery or administration of the VAD substance can take place over telephone, video conference, email, fax or other forms of electronic communication. This disrupts and delays the delivery of high-quality, timely and accessible VAD care.

There is uncertainty about the extent to which the provisions apply to VAD communication, with a high level of concern that it may affect all conversations or information shared about VAD that uses a carriage service.

Some examples of the impact include:

- Even a person who is frail, suffering and in pain must attend all appointments in-person, or wait for a health professional to visit them at home. Sadly, some people have died waiting for at-home assessment.
- People in regional and remote areas face additional barriers to accessing VAD care as travel is required for all steps and stages of the VAD process.
- No follow-up information or support can be provided beyond in-person appointments (e.g. a pharmacist who delivers VAD medication to a person's home can only provide follow-up information by another visit).
- Prescriptions for the VAD substance must be hand-delivered to pharmacies.
- Doctors, nurses, pharmacists and allied health professionals making arrangements to support the administration of the VAD substance break the law if they email, fax, call or text each other.

Person centred communication is essential for the delivery of high-quality and safe health care. Health professionals and patients are best placed to decide which communication methods are appropriate, in line with Ahpra telehealth guidance and in accordance with their professional body's Code of Conduct (e.g. Medical Board of Australia's Code of Conduct, Ahpra's Shared Code of Conduct, Ahpra's Nursing and Midwifery Board's Code of Conduct).

Legal restrictions on communication methods do not apply to any other area of health care, and limit the ability of health professionals to do their jobs and provide the best care.

August 2024
Coordinated by
Go Gentle Australia

We are a ACNC registered charity with DGR1 status. Donations over $2 are tax deductible.

Go Gentle Australia was established in 2016 and played a critical role in the introduction of voluntary assisted dying laws across Australia. Our charity works nationally to promote choice at the end of life. We empower people to choose the care that is right for them, including the option of voluntary assisted dying. We believe the voices of dying people should be heard and their decisions respected.

Published August 2024

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

Contact Us

Phone: 0468 464 360
Email: policy@gogentleaustralia.org.au
Write: PO Box Q46, QVB NSW, 1230
ABN: 61 613 668 643

www.gogentleaustralia.org.au

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