

Report into Voluntary Assisted Dying in the Northern Territory

FINAL REPORT 2024

Acknowledgement of Country

We acknowledge the Australian Aboriginal and Torres Strait Islander peoples of this nation. We acknowledge the traditional custodians of the lands and waters. We pay our respects to ancestors and Elders, past, present and emerging. We are committed to honouring Australian Aboriginal and Torres Strait Islander peoples' unique cultural and spiritual relationships to the land, waters and seas and their rich contributions to society.

Terminology in this Report

While this Report uses the term 'Aboriginal', we respectfully acknowledge that Torres Strait Islander peoples are First Nations peoples living in the NT, and 'Aboriginal' Territorians should be read to include both Aboriginal and Torres Strait Islander Territorians.

If reading this Report has raised distressing issues for you the following helplines can be contacted for support:

Lifeline 13 11 14 (available 24/7) (lifeline.org.au)

Beyond Blue 1300 224 636 (beyondblue.org.au)

Kids Helpline 1800 551 800 (kidshelpline.com.au)

NT Mental Health Line 1800 682 288

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The Honourable Eva Lawler MLA
Chief Minister of the NT
5th Floor Parliament House
Mitchell Street
Darwin NT 0800

Dear Chief Minister,

On behalf of the Voluntary Assisted Dying Independent Expert Advisory Panel we commend to you our Report, containing recommendations, for consideration and the potential development of the Northern Territory Voluntary Assisted Dying legislation.

As per our Terms of Reference during the period 22 August 2023 to 23 May 2024 we engaged with a broad range of Territorians. We travelled across the Northern Territory to participate in public consultation through multiple avenues including visits to Darwin, Palmerston, Katherine, Alice Springs, Nhulunbuy, Jabiru, Tennant Creek and Wadeye for public and requested meetings. We have also undertaken research about voluntary assisted dying to learn from other jurisdictions in Australia and overseas.

To assist and inform Territorians we prepared invaluable discussion guides on a wide range of topics including,

1. What is VAD and how to have your say,
2. Who should have access to VAD?
3. What process to follow to access VAD,
4. The role of health professionals and health services,
5. Monitoring and compliance, and a VAD Jurisdictional Comparator Table.

We also established a dedicated website, an online survey, and a hotline to receive enquires and assist the public on how to gain information or make a submission. Overall our weekly consultations with key individuals, experts, special interest groups, organisations and community groups has been instructive and certainly informed the Panel's recommendations. We have heard from more than 350 individual participants through public forums and other meetings, met with around 60 organisations, received 98 written submissions and almost 1400 survey responses.

The Panel has been mindful of engaging extensively. It can be expected that some people in the community will not support all of our recommendations and there will be concerns about the prospective legislation and the impact it may have on them and their communities. We have heard divergent views from those who oppose voluntary assisted dying and that is included in our Report. On balance our Report reflects the view of the majority of Territorians who have engaged with the Panel. We are extremely grateful to the many individuals and families who shared with us their deeply personal and very poignant life stories.

We extend our utmost appreciation to each Panel member, they have been generous with their time and expertise. We thank them for their support, wise counsel and significant contribution at regular meetings for the duration of the consultation and engagement period, and with the preparation of this Report.

On behalf of the Panel we acknowledge the Secretariat team in the Priorities Delivery Unit, Department of the Chief Minister and Cabinet. Their dedication and professionalism throughout the many phases of the process has been invaluable. This is a sensitive topic that requires a considered and empathetic approach and a lot of skill and knowledge to manage appropriately, they have displayed this at every turn.



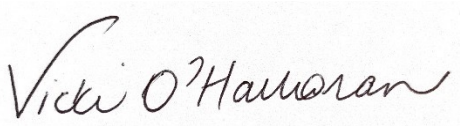
Although it is not within the Panel's Terms of Reference we believe we should convey to you a strong body of opinion that has been expressed during the consultation period, that there should be legislation to enable a person, whilst they still have capacity to express in an advance personal plan/health directive, a wish to access voluntary assisted dying in preparation for their end-of-life. Panel members have always explained this matter does not directly form part of our Terms of Reference but feel that it is important to bring to your attention what we have heard when it is of a consistent nature during engagement.

We recognise this Report forms part of a crucial piece of public policy, with the potential to reshape the end-of-life outcomes for individuals and families who reside in our Northern Territory.

Finally, it has been an honour for us to lead this Panel on this important topic and engage with people about what is pertinent to them. We feel a deep sense of commitment to our Territory and its valued and indispensable role in the Australian community in advancing the rights of those who choose to live here.

We trust this Report is of assistance to you Chief Minister in advancing the issue of voluntary assisted dying in the Northern Territory as you see fit to the benefit of Territorians.

Yours sincerely,



Vicki O'Halloran, AO CVO
Co-Chair
Expert Advisory Panel



Duncan McConnel, SC
Co-Chair
Expert Advisory Panel



Executive Summary

Voluntary Assisted Dying (VAD) legislation has now been passed in all Australian States and Territories, except for the Northern Territory (NT). In August 2023, an independent Expert Advisory Panel was established by the Chief Minister of the NT to inquire into and report on developing VAD legislation in the NT. This Report presents the consultation process, findings and recommendations of the Panel.

Context

VAD was briefly legal in the NT under the *1995 Rights of the Terminally Ill Act*; the first jurisdiction in Australia to have such laws. Subsequent federal legislation prohibited the NT from making such laws from 1997 until December 2022, with the NT now able to legislate on this important subject.

The NT covers a large land area with a relatively small population of about 250,000. About 50 per cent of Territorians live in regional and remote areas, and about one third identify as Aboriginal and Torres Strait Islander. The Territory also boasts a large migrant population. Health care needs of Territorians are also unique, with a 77% higher burden of disease compared to the rest of Australia. These are all important considerations in relation to VAD.

Panel and Consultation Process

The Expert Advisory Panel, co-chaired by the Hon Vicki O'Halloran AO CVO and Duncan McConnell SC, included expertise from clinical, legal, consumer, disability, and culturally and linguistically diverse groups, including two Indigenous panel members. The Panel undertook extensive public consultation between August 2023 and April 2024 to hear Territorians' views on how potential VAD legislation should be developed and implemented. This was guided by five community discussion guides (Appendix 1) and one clinical discussion guide, which were distributed widely. This consultation process included: an online survey, receiving 1,396 responses; 98 written submissions, public community forums, stakeholder roundtables and meetings with topic experts, including 56 organisations. The Panel prioritised engaging with Aboriginal and Torres Strait Islander Territorians and organisations, as well as rural and remote stakeholders.

In reaching its conclusions, the Panel also spoke to individuals and organisations in other jurisdictions to understand their VAD experiences and considered the extensive body of research on VAD. The Panel respected the diversity of feedback and considered it all through its four key guiding principles: Engage, Listen, Respect, Report.

Next steps

This Report will undergo consideration by government, and if supported, recommendations would inform draft legislation for VAD in the NT. The agency tasked with responsibility for VAD services should consider all of the recommendations and findings contained in this Report, when designing and implementing delivery of future VAD services in the NT.



No.	Recommendation	Chapter
1	The NT should implement VAD legislation that is broadly consistent with VAD legislation in other Australian States and Territories	1
2	The NT should develop and fund a single, centralised service for the delivery of VAD. This should include VAD practitioners, pharmacists and care navigators. Due to the very specific cultural safety concerns related to provision of VAD, the service should be stand-alone, and clearly separate from existing NT Health facilities.	2
3	VAD assessments must be conducted by appropriately trained medical practitioners only. VAD practitioners must undergo mandatory training and hold appropriate qualifications	2
4	Health professionals should be allowed to conscientiously object to participating in any VAD framework under NT legislation. Conscientious objectors should be required to inform requesting patients of VAD services. Residential facilities may not hinder residents from accessing VAD on site.	2
5	Interpreters must be accredited in order to provide interpreter services in VAD. At every stage of the VAD process, where an interpreter is used, their involvement should be documented and the interpreter should certify their participation accordingly.	2
6	The process for addressing Aboriginal and Torres Strait Islander cultural safety issues needs to be designed and resourced as a core part of the operationalisation of VAD.	3
7	Recognising the importance of palliative care services in the NT: - A person who requests VAD must be informed of all treatment options including the nature, scope and availability of palliative care services. - Further resources should be provided to educate the community about the nature and scope of palliative care options, particularly for people who wish to remain at home. - Palliative care services must be consistently and adequately resourced to provide specialised and holistic palliative care to patients, wherever they live in the NT and to address the gaps in those services that result in inequities in people's end-of-life options. Implementation of VAD services in the NT must be complementary to, not at the expense of, expanded palliative care resources.	3
8	To access VAD in the NT, a person should have ordinarily resided in Australia for two years and in the Territory for 12 months. Exceptions should apply for cross-border communities and those with personal connections to the NT, particularly in relation to family, cultural and/or support links.	4
9	To access VAD in the NT, a person should be aged 18 years or older.	4
10	To access VAD in the NT, a person should have a serious and incurable condition which is causing intolerable and enduring suffering that cannot be relieved in a manner they feel is acceptable. VAD eligibility should be based on a prognosis of 12 months at the time of being assessed, irrespective of diagnosis and if the patient meets all other requirements.	4

No.	Recommendation	Chapter
11	To access VAD in the NT, a person must have decision-making capacity at all stages. VAD should not be available for persons solely diagnosed with a mental illness.	4
12	Medical practitioners should be allowed to introduce the subject of VAD services to patients during discussion about treatment options.	5
13	Subject to amendment of Commonwealth legislation, telehealth should be permitted for VAD purposes provided at least one assessment is conducted in person.	5
14	The VAD assessment process should involve two stages of assessment conducted by appropriately qualified medical practitioners.	5
15	Following the assessment phase, the person must make a formal request for VAD in writing which is independently witnessed. Provision should be made where a person is physically unable to provide a formal written request. The timeframe before a formal request may be made should be broadly consistent with timeframes in VAD legislation in other Australian jurisdictions.	5
16	The VAD process should not require the issuing of a permit but rather allow the Coordinating Practitioner to approve the request and issue a prescription, subject to strict reporting requirements.	5
17	The VAD legislation should provide for safe supply, storage and disposal of the substance, including a contact person for VAD. The VAD legislation should provide for a contact person to be appointed by a person who elects self-administration for VAD.	5
18	The Contact Person and Coordinating Practitioner must notify the Review Board of all deaths of persons who have made a formal request for VAD. Notification to the Coroner should not be specifically required. The cause of death of a person who has died by VAD should be the underlying disease or illness that would have led to the person's death without VAD.	5
19	An independent statutory body (Review Board) should be established to monitor compliance in every case and to review the operation of the Act. The functions, membership and responsibilities of the Review Board should be as outlined in Chapter 6 of this Report.	6
20	There should be a right of review to the NTCAT for some VAD decisions on eligibility, limited to only the person seeking access to VAD. The VAD legislation should expressly preserve the inherent jurisdiction of the Supreme Court.	6
21	The first review of the operation of the NT VAD legislation should be delivered as soon as practicable after the third anniversary of its commencement. After that, reviews should be conducted at five year intervals.	6
22	VAD services should be ready for operational implementation within 18 months of the legislation being enacted.	7



01 CONTEXT





1.1. Introduction

On 22 July 2023, the Chief Minister of the NT, the Hon Natasha Fyles MLA, announced an Expert Advisory Panel would inquire into and report on developing VAD legislation in the NT.

The Panel began investigations and consultations in August 2023, guided by the Terms of Reference (Appendix 2) questions:

- i. What can the NT learn from the VAD experience in other jurisdictions, including overseas?
- ii. Who should be able to access VAD?
- iii. What process should a person follow to access VAD?
- iv. What models of care should be adopted so that VAD can effectively be delivered in the NT context?
- v. What are the legal and ethical obligations of Health Practitioners who provide services relating to VAD?
- vi. What safeguards need to be put in place for those accessing or providing VAD?
- vii. How should compliance be monitored?
- viii. Any other question the panel considers appropriate.

The Panel also committed to four key guiding principles:

Engage – Listen – Respect – Report

Engage broadly across the community in a culturally safe way, providing opportunities for open discussions and sharing of information.

Listen to the community, including individuals and representative organisations, hearing the stories, concerns and aspirations of Territorians.

Respect the views of all participants whether provided through public meetings, discreet consultations, online survey or written submissions.

Report to the NT Government – providing recommendations to guide the development of a new statutory framework on VAD legislation.

This Report articulates the Panel's recommendations to the Chief Minister and the basis for those recommendations. The Panel's recommendations are informed by an extensive consultation process throughout the Territory, research on VAD legislation in other jurisdictions, submissions received and the Panel's own expertise and experience.

The Panel would like to thank the individuals and organisations who provided written submissions, oral submissions, attended the public forums or completed the online survey. In particular, the Panel would like to thank those Territorians who shared stories of their loved ones with the Panel.

The Panel members are grateful for the high level of engagement and ongoing participation in the consultation process from members of the public and organisations. We understand that death and dying are sensitive topics and were overwhelmed by people's generosity in sharing their personal stories and intimate moments around end-of-life care. Every response has been valuable in shaping the Panel's final recommendations.

The Panel also acknowledges the support team for the assistance provided throughout the course of the Panel's investigations and deliberations.





Social Regulation
Be cautious
Watch out for...
Lect

Should I just be myself?

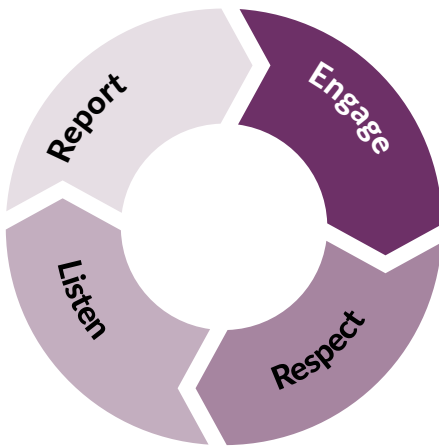
1. Have your goal
2. Play at your own risk

Cautious
Unconscious

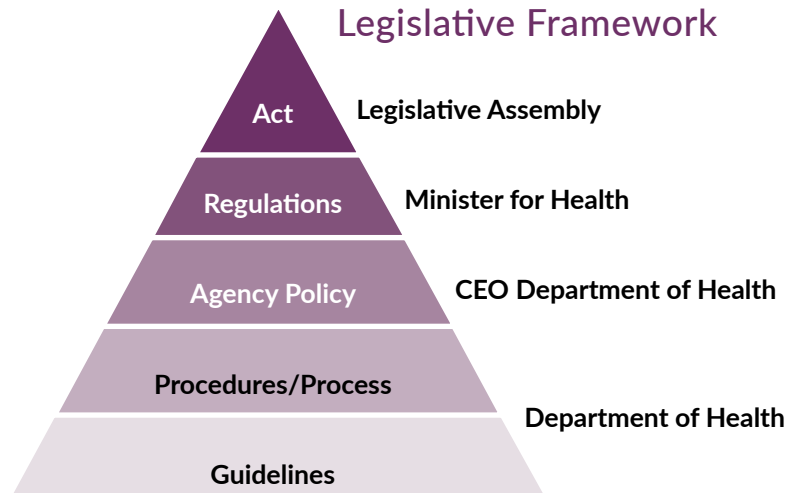
VAD – Governance Framework

The following diagram summarises the Panel's proposed process for VAD.

Guiding Principles



Legislative Framework



Review Board - Independent Statutory Body

Appointed by: Minister

Comprising: legal, medical and community representatives

Roles and responsibilities: Review and report on each case, commission legislative review

Territory-wide VAD service

VAD Practitioners

Comprising: appropriately qualified medical practitioners (for consulting and coordinating practitioners) and AHPRA- registered health practitioners (administering practitioners)

Roles and responsibilities: provide consulting and coordinating assessments to patients, and administration of substance if appropriate.

VAD Care Navigators

Comprising: appropriately qualified allied health practitioners

Roles and responsibilities: provide information about VAD, support patients, carers and health practitioners through process.

VAD Pharmacy Service

Comprising: Pharmacists

Roles and responsibilities: Substance education, coordination of substance supply, secure storage and return if appropriate.

Appeals Process

Applicant may appeal some eligibility decisions to NT Civil and Administrative Tribunal (NTCAT)

The Expert Advisory Panel



Hon Vicki O'Halloran AO CVO (Panel Co-Chair)

The Honourable Vicki O'Halloran AO CVO was sworn in as the 22nd Administrator of the NT on 31 October 2017 and remained in office until 30 January 2023. Prior to her appointment as Administrator, Her Honour was Chief Executive Officer of Somerville Community Services.



Duncan McConnel SC (Panel Co-Chair)

Duncan McConnel SC is a senior counsel practising at the NT Bar, having practised as a lawyer in the Territory for more than 30 years. Duncan is a former president of the Law Society NT and NT Bar Association and in 2015 became the second only national president of the Law Council of Australia from the NT. Duncan is the Chair of the NT Legal Aid Commission.



Dr Geetanjali Lamba

Dr Geetanjali Lamba is a medical doctor and public health physician at NT Health. She is also a senior lecturer at Charles Darwin University Menzies School of Medicine and public health lecturer at the Menzies School of Health Research. Since 2020, Dr Lamba has been actively immersed in VAD implementation research at Monash University.



Dr Devaki Monani

Dr Devaki Monani is a lecturer in social work at Charles Darwin University (CDU). She teaches ethics, rights and social justice and is the chair of the Ministerial Advisory Council on Multicultural Affairs (2023-2025). Dr Monani is also a senior research fellow (adjunct) at the Sir Zelman Cowen Centre, Victoria University and honorary fellow at the NT Menzies School of Health Research.



Wendy Morton

Wendy Morton has worked in the NT disability sector and community legal services for many years. She spent 14 years as the Executive Director of the NT Council of Social Service (NTCOSS) and in 2021 became the NT Community Housing Registrar.

The Expert Advisory Panel



Ursula Raymond

Ursula Raymond is a former ABC journalist/broadcaster, ministerial adviser and senior policy adviser. She worked with former NT Chief Minister Marshall Perron on recent attempts to revive VAD laws. As the Deputy NT Treaty Commissioner from June 2019 to June 2022, she led community consultations with Aboriginal Territorians on a treaty, land rights, tourism and arts practices.



Dr Christine Sanderson

Dr Christine Sanderson is a palliative medicine physician with a sociology degree and a Masters in Public Health. She is on the Council of the Australian New Zealand Society for Palliative Medicine and is the Medical Director of Territory Palliative Care Central Australia, based in Alice Springs.



Sue Shearer

Sue Shearer has been the Chief Executive Officer of COTA NT (Council of the Ageing) since February 2017. Mrs Shearer's role has grown exponentially as COTA NT's advocacy and opinion is increasingly sought by seniors and stakeholders in the NT.



Dr Kane Vellar

Dr Kane Vellar is a staff specialist with NT Health working across a range of specialties, including: Psychiatry, Palliative Care and Psycho-Oncology. He is a clinical associate professor with Charles Darwin University Menzies School of Medicine and passionate about supporting their First Nations pathway program.



1.2. Key Terms

VAD is a complex issue that demonstrates the diversity of views and values held across the community. The term 'voluntary assisted dying' is widely used in Australia and is the term adopted by the Panel.

VAD (VAD) is the use of a prescribed substance to cause the death of a person with a terminal illness at their request.

It is an end-of-life choice which allows eligible people who are dying to choose the timing and circumstances of their death. It is an option that can limit suffering at the end-of-life. It is not a way to end life for those who are not dying. It is not suicide. Other end-of-life choices include continuing with treatment to try to remedy the condition, or receiving palliative care.

Other terms used in the Report include:

Advance Personal Plan	An Advance Personal Plan is the document in which a person can nominate their preferred health care decision-maker.
Administration	The act of administering the substance used for VAD.
Capacity	The power/ability to do something. To have the ability to make reasoned decisions for yourself about your personal, financial and legal matters.
Centralised service	A stand-alone single service for the delivery of VAD. It would help address the NT's unique cultural, demo-graphic and geographic issues.
Coercion	The act or power of compelling someone into an action.
Conscientious objection	Means a person declines to participate in a lawful process, such as voluntary assisted dying, due to their personal beliefs, values, or moral concerns.
End-of-life care	Care provided to a patient during the last stages of life.
Euthanasia	The word euthanasia is derived from the Greek word of euthana-tos meaning 'easy death'. Generally it is used to describe the process of intentionally terminating a person's life to reduce their pain and suffering.
Life-limiting illness	A life-limiting illness is an active, progressive, or advanced disease, that has little or no prospect of cure and that you're likely to die from at some point in the future.
Navigation Service	A service to provide accessible information and support to individuals considering VAD, their families, caregivers and health professionals, and to facilitate connections with participating medical professionals.
Palliative care	Health care that focuses on improving the quality of life and quality of care for people with a life-limiting illness.
Self-Administration	The act of dispensing a substance to yourself.
Substance	The clinically approved substances for the purpose of VAD.
Terminal Illness	A terminal illness is a medical condition which is incurable and causes inevitable early death.

1.3. VAD Overview

1.3.1. A short history of VAD in the NT

The NT was the first jurisdiction in the world to legalise VAD with the *Rights of the Terminally Ill Act 1995* (NT) (the ROTI Act). The Act came into operation in 1996.

The ROTI Act permitted a terminally ill person to end their life with medical assistance, either by the direct involvement of a physician or by procurement of drugs. Under the ROTI Act, the person had to be over 18 years of age and be mentally and physically competent to request their own death. The request had to be supported by three doctors, including a specialist who confirmed that the person was terminally ill and a psychiatrist who certified that the person was not suffering from treatable depression. Once the request was approved by the medical practitioner, a nine day “cooling off period” was required before the death could proceed.

During the seven months between July 1996 and March 1997 when the ROTI Act was in force, four people with terminal conditions accessed the ROTI Act and were supported through voluntary assisted dying. They included Territorian Bob Dent. Prior to his death from prostate cancer on 22 September 1996, Mr Dent wrote:

“If you disagree with voluntary euthanasia, then don’t use it, but don’t deny me the right to use it if and when I want to... I am immensely grateful that I have had the opportunity to use the Rights of the Terminally Ill Act to ask my doctor ... to assist me to end this interminable suffering and to end my life in a dignified and compassionate manner.”

In March 1997, the *Euthanasia Laws Act 1997*(Cth) came into force. The legislation effectively prohibited self-governing Territories in Australia from making laws in relation to voluntary assisted dying.

After many attempts to repeal the *Euthanasia Laws Act 1997* (Cth), the *Restoring Territory Rights Act 2022* (Cth) passed in the Federal Parliament on 1 December 2022. The Act removes the restriction preventing the Territories from passing legislation in relation to voluntary assisted dying. The Restoring Territory Rights Act 2022 (Cth) does not legalise VAD but it gives Territories the right to pass laws allowing for voluntary assisted dying.

1.3.2. The Need for Legislation

As the law in the NT currently stands, the self-administration of a substance to kill oneself, and which results in death, is suicide. It is an offence to assist another person to kill themselves.

VAD legislation alters that law in defined circumstances and provides a legally authorised option for a dying person to hasten their death by medical assistance.

All VAD legislation in Australia provides protections for health practitioners who assist persons to die under the legislation. Health practitioners who act in accordance with the legislation will not be liable for homicide or the crime of assisting suicide.

In all Australian States, except Victoria, the VAD legislation provides that someone who ends their life in accordance with the legislation does not die by suicide. In those jurisdictions, a person is considered to have died from the disease, illness or medical condition from which they were dying and which made them eligible at the end of their life to access voluntary assisted dying.



1.3.3. National Laws

VAD is lawful in all Australian States and the Australian Capital Territory. The table at Appendix 3 provides an overview and comparison of the legislation across Australia. While each jurisdiction's laws are similar, there are some key differences.

For example, while eligibility criteria are generally similar (must be 18 or over, must be an Australian citizen or permanent resident), in Victoria, South Australia and Tasmania the illness must be incurable, and in Tasmania it must be irreversible.

Also, in Victoria, South Australia and Tasmania the VAD substance must be self-administered unless the person is incapable of self-administration. In Queensland, Western Australia and New South Wales, it is the person's choice whether to self-administer or be assisted by a health practitioner.

In all States a health practitioner can conscientiously object to participating in VAD. In Victoria, South Australia, Queensland and New South Wales a person with a conscientious objection can refuse to provide information about voluntary assisted dying. In Western Australia, Queensland and New South Wales a medical practitioner who refuses to accept a referral for VAD because of a conscientious objection must let the person know immediately. In Western Australia, Tasmania and Queensland there is a mandatory obligation to provide contact details of a doctor or service which provides VAD assistance to the person.

The Panel considers that such key differences could be at least partly resolved by a process of alignment or national harmonisation of VAD laws, regulations and processes in Australia.



1.4. NT Profile

The NT has unique geographical and demographic features. It covers a large land area of 1.35 million square kilometres with a population of about 250,700 people¹. While a significant proportion reside in urban hubs like Darwin and Alice Springs, nearly 50 per cent of the population is widely distributed across rural and remote areas, surpassing the national average of 22 per cent².

Aboriginal Territorians make up 31 per cent of the total population of the NT with 80 per cent of Aboriginal Territorians living in rural or remote areas³.

The median age of Territorians is 33 years of age. However, the Aboriginal population in the NT is younger than the non-Aboriginal population with 46.8 per cent of Aboriginal Territorians being under 25 years of age⁴.

The NT boasts cultural and linguistic diversity, with more than 200 different languages spoken. These unique characteristics coupled with challenges arising from geography, climate and the vast spread of communities, collectively influence the provision of health services.

Burden of Disease in the NT

The NT has a unique disease profile in comparison to the rest of Australia. In the NT, poor health outcomes are also influenced by social determinants such as social disadvantage, poverty, and low health literacy. A detailed explanation of the Burden of Disease in the NT is at Appendix 4.

Living in remote and very remote areas is associated with a higher burden of disease, and also makes access to health care, including VAD services, more challenging.

As a result, individuals seeking VAD in the NT, may face additional challenges related to their socio-economic circumstances. These factors must be considered in the development of VAD services in the NT.

Availability and accessibility of health care

The Department of Health (NT Health) manages the public health system in the NT. NT Health provide a spectrum of health services from health promotion, prevention, treatment, rehabilitation and palliative care.

Public health services are provided across six public hospitals – two in Greater Darwin and one in each of Alice Springs, Tennant Creek, Katherine and Gove. The hospital bed numbers are as follows: Royal Darwin Hospital (360), Palmerston Regional Hospital (116), Alice Springs Hospital (165), Tennant Creek Hospital (20), Katherine Hospital (60), Gove District Hospital (30).

NT Health also provides 39 primary health care centres and supports 133 services operated by Aboriginal Community Controlled Health Organisations (ACCHOs) throughout the NT.

The NT confronts considerable challenges in delivering health care, some of which are universal, while others are specific to the region. Issues include an aging population, a rising prevalence of chronic conditions, an over-reliance on acute care, difficulties attracting and retaining a skilled workforce, as well as significant socioeconomic disadvantage and geographic and cultural barriers to providing care.

¹ NT Government, Department of Health, *Annual Report 2022-2023* (Report, 2023) page 9.

² Rural and remote health - Australian Institute of Health and Welfare (aihw.gov.au)

³ Ibid.

⁴ Ibid.

Availability and accessibility of aged care

The NT hosts 895 residential aged care places distributed among nine mainstream Residential Aged Care Services (RACS) situated in urban and regional areas and ten National Aboriginal and Torres Strait Islander Flexible Aged Care (NATSIFAC) residential services spanning rural and remote regions of the NT.

To support senior Australians, the Australian Government offers various services, including the Commonwealth Home Support Program (CHSP) designed to facilitate access to entry-level support services, enabling independent and safe living at home.

Additionally, home care packages are available for seniors with more intricate care needs that surpass the scope of CHSP. Transition care is also provided to aid in the recovery process following a hospital stay. However, it is worth noting that coverage of services outside of Darwin and Alice Springs is limited.

As with palliative care services, the provision of aged care services in rural and remote areas is challenging, with significant workforce and funding constraints. Residents in these areas continue to face difficulties in accessing these services and often need to move a long way from home and family should they require residential aged care.

The NT also has the highest growth in population over 65 years in Australia (ABS 2021 Census DATA). This, coupled with dementia being the fastest growing disease in Australia, means that the demand for home care packages and residential care, including for dementia patients is at a critical level in the NT.



1.5. Consultation Methodology

From 22 August 2023 to 30 April 2024, the Panel undertook an extensive public consultation process to hear Territorians' views on the potential development and implementation of a new statutory framework for VAD. The consultation was guided by the questions set out in the Terms of Reference. Five discussion guides (Appendix 1) were released to the public providing information about VAD and covering a range of issues being addressed through consultation. A clinical discussion guide (Appendix 5) was developed for medical professionals to gain further background on potential clinical models and issues.

Throughout the consultation process, the Panel listened to a wide range of views. The Panel acknowledged this diversity of feedback through its four key guiding principles outlined at the beginning of this Report – Engage, Listen, Respect, Report.

Avenues for consultation and feedback

There were multiple ways for people and organisations to provide their views during the consultation process, including:

- community consultation meetings in every regional centre;
- an online survey;
- written submission via email or post;
- a hotline phone number; and
- stakeholder meetings with groups, individuals and organisations.

These avenues were advertised across the NT via newspaper, radio, social media and regional networks.

What we heard

Consultation was divided into stakeholder and community consultation meetings. Stakeholders were identified across priority areas including health, legal, community services, disability, multicultural, community controlled and religious sectors. Stakeholder meetings were held with individuals and organisations who were identified or requested to meet with the Panel. Community consultation meetings were held in every region of the NT (defined by the NT Government) and were publicly advertised for all Territorians to attend. Appendix 6 provides figures around those meetings and the number of public submissions received by the Panel.

Across the consultations and through the public submissions, common issues emerged. These included:

- the importance of ensuring culturally safe regional and remote consultation practices;
- concerns that Aboriginal cultures and customs will not align with VAD;
- views that VAD should not occur in hospitals or hospices;
- ensuring adequate safeguards for medical practitioners and patients;
- the need for increased resources for palliative care services across the NT;
- ensuring legal protections for conscientious objectors;
- the importance of ensuring VAD legislation included protections for vulnerable people;
- minimising 'red tape' for any NT legislation and VAD process;
- whether VAD could be included in Advance Personal Plans to address fears about dementia;
- how and when telehealth could be used; and
- avoiding overly restrictive timeframes for prognosis.



Regional and remote consultation

Hearing the views of Territorians in regional and remote areas of the NT was a priority for the Panel. This included speaking to both Aboriginal and non-Aboriginal Territorians in their communities.

The NT's unique circumstances in terms of population, access to services, distance to regional centres, population movement, seasonal changes, staff turnover and service delivery were recognised by the Panel as factors that needed to be considered during the consultation process and in the development of the recommendations.

Organisations representing pastoralists and remote services were contacted to engage with their members and provide feedback.

Aboriginal Territorians

Discussing VAD with Aboriginal Territorians in a culturally safe way was also a priority for the Panel.

A variety of resources were developed to assist with education and consultation about VAD in remote Aboriginal communities. These included plain language guides and posters, voice recordings, radio advertising and targeted social media postings.

Voice recordings were available in 14 languages and included Alywarr, Anmatyerr, Burarra, Eastern Central Arrernte, East side Kriol, Kunwinjku, Maung, Pintupi Luritja, Pitjantjatjara, Tiwi, West side Kriol, Warlpiri, Western Arrarnta, and Yolngu Matha.

Aboriginal views, concerns and comments raised with the Panel are outlined in more depth in Chapter 3 – Views on VAD.



Survey results*

A total of 1396 survey responses were recorded through the Have Your Say survey which was open for four months from November 2023 to March 2024. Further detail about the content of survey results is in Appendix 7.

Some of the responses (in per centages) were:

	Agree	Neither agree nor disagree	Disagree
A person should be able to choose when they die	73%	0%	27%
I am aware of the VAD legislation in other States and Territories in Australia	85%	7%	8%
A person should have a terminal illness diagnosis to access voluntary assisted dying	52%	9%	39%
A person should be able to access VAD if they only have a mental health condition as the reason for their access	28%	16%	56%
Someone should only be allowed to access VAD if, regardless of their life expectancy timeline, they are dying from a terminal and progressive illness	53%	7%	40%
A person who is ordinarily a resident in another State or Territory in Australia but wants to access VAD in the NT (due to cultural or family connections), should be able to do so	69%	9%	22%
A person should be required to make multiple requests to access voluntary assisted dying	40%	16%	44%
Someone should be able to say in their advanced care plan that they want to have the option for VAD in the future, even if they don't have the capacity to make that decision themselves at the time, due to something like dementia	71%	4%	25%

* Note: The online survey had no restrictions on the number of times someone could respond and no limitations on where a respondent was based.

1.6. Conclusions

Overwhelmingly, the Panel's consultations demonstrated the community supports the return of VAD legislation to the NT. With some notable and understandable exceptions, most respondents recognised that VAD is a personal choice and that even individual philosophical or personal opposition to VAD should not prevent access for those who wish to do so, provided that appropriate safeguards exist. Generally speaking, the safeguards which exist in other Australian VAD legislation were considered appropriate.

RECOMMENDATION 1

The NT should implement VAD legislation that is broadly consistent with VAD legislation in other Australian States and Territories.



02

SERVICE DELIVERY



2. A Unique Territory Model for VAD

2.1. A centralised model for delivery of VAD

The Panel consulted widely regarding the framework and process that would be the most suitable in the NT context. As part of those consultations, the Panel examined the frameworks for access to VAD in other Australian jurisdictions and internationally.

In community consultations, the Panel encouraged feedback from members of the public regarding all aspects of the VAD process including:

- how a person may initiate a request for VAD;
- whether an assessment of eligibility for VAD should be undertaken by a medical specialist and the level; of experience and specialisation appropriate in the NT;
- the number of steps required to be undertaken in the assessment process leading to final approval and administration of VAD;
- the timeframe over which the assessment process could take place, including any “cooling off” period;
- any requirement for the request for VAD to be in writing or otherwise confirmed other than orally;
- whether a witness to a request for VAD was required; and
- any restrictions or conditions to be imposed on persons acting as a witness where they may gain a benefit from the passing of the person requesting VAD.

The process by which VAD is accessed in other States in Australia is essentially community-based. A person who seeks to access VAD must initiate a request, usually from their treating medical practitioner. If their treating medical practitioner is a conscientious objector or does not have the necessary approvals to participate in VAD assessments, the person may be referred to an eligible treating medical practitioner or a navigator service.

A summary of the process followed in other jurisdictions in Australia is set out in Appendix 8.

There are a number of acknowledged challenges in the NT in delivering VAD services. They include:

- the ability to access medical practitioners outside of the major centres of Darwin and Alice Springs;
- the potential risk to clinical staff in small or remote communities if it was publicly known they were, or willing to be, involved in VAD assessments; and
- the impracticalities of operating a community-based model in remote or regional areas.

These culturally and geographically unique features of the NT led the Panel to conclude that a different, centralised model for VAD would be necessary in the NT to ensure equity of access, cultural safety and to provide the right balance of safeguards in any VAD regime.

A centralised model of VAD service delivery for the NT would follow essentially the same processes as are in place in most other jurisdictions but would be managed and administered centrally by a service team working under the direct control of an oversight body such as a Board or Commission.

The Panel considered that the centralised model should comprise a multi-disciplinary service covering all facets of the VAD process including:

- clinicians to undertake all assessments and coordination;
- VAD navigation services including liaison with interpreters, family support, counselling, social supports and bereavement support; and



- pharmacy services to manage and oversee all aspects of substance control, distribution and disposal.

If a centralised VAD service model is adopted, the community can be confident that those who are practising within the area of VAD are appropriately qualified, trained and experienced and have access to all necessary resources and support.

A centralised model, with trained doctors available to participate in the service on an on-call basis and as part of a functioning multidisciplinary team, would allow for certainty of access to the medical components of the process, and once fully staffed it would ensure that all VAD processes could be completed in a timely way.

In its consultations, the Panel found that there was broad agreement, particularly amongst clinicians, that the model would provide additional advantages:

- the development of a highly skilled team of clinicians with the relevant expertise, who could case-manage the processes of VAD assessment and provision for individual patients would ensure VAD is accessed safely and appropriately, and that all the processes are timely;
- it would enable the separation of the processes associated with VAD from usual clinical practice, as advocated by many clinicians working in hospital practice or in remote clinics and so would mitigate some of the clearly identified cultural risks associated with the introduction of VAD;
- for participating medical practitioners, it offers separation from their other clinical roles, support as they undertake the activities involved, and reasonable reimbursement for the work that they do in relation to VAD;
- it reduces the prospect of barriers to access due to conscientious objection - it limits their clinical responsibility to either providing a referral, or giving information that will assist a patient to self-refer to the service; and
- it enhances monitoring and reporting with regard to the safety, accessibility and outcomes of the service.

“We support a centralised, stand-alone model of service delivery, outside the hospital system.”
 – Heads of Departments, Alice Springs Hospital, Submission 80

These benefits are significant and address many of the most serious concerns with VAD processes, as implemented in other jurisdictions.

The Panel acknowledges a centralised VAD model would require additional resourcing by government but considers that this would address concerns identified in other States and Territories with the community based model and cost implications. In other States, most of the non-medical components of VAD services are funded – these usually include the VAD Care Navigators, pharmacists, other support staff who may have been employed such as nurses, social workers or psychologists, administrative staff, and managers. The extent to which these staff are co-located or function as a team varies from state to state.

Medical practitioners in private practice are not funded as part of the established VAD services in most, if not all, other jurisdictions. There is no Australian Government funding available through Medicare for medical activities related to VAD, nor can it currently be covered by private health insurance. As a result, much of the medical contribution to the VAD process that occurs in other jurisdictions is unfunded, is being managed by clinicians in addition to their existing workload, or is occurring under private arrangements between patients and their doctors. Some jurisdictions or organisations are exploring options to fund the medical component of VAD by developing a public outpatient clinic for VAD. For example, the South Australian VAD service team told Panel members they are “slowly seeing the creation of outpatient capacity in metro hospitals”.

This ad hoc and patchy approach to VAD service development has led to real difficulties for doctors who may wish to participate, but for whom the training for VAD and the work associated with delivering VAD can be extremely burdensome taking periods of long consultation that financially and operationally impact their practice. This may preclude some clinicians from starting or continuing to provide VAD. It is associated with risk of burnout for others, and means that the pool of involved doctors is likely to remain small.



Care Navigator Service

VAD Care Navigator Services have been established in Australian jurisdictions where VAD is legislated. The role of the Care Navigator Service has been to provide accessible information and support to individuals considering this option, their families, caregivers, and health professionals, and to facilitate connections with participating doctors. Finding the timely and necessary information and support to manage the complexities involved in the VAD process is critical.

In Canada, several provinces and territories have established centralised care coordination services, which employ appropriately trained clinicians who can support and inform individuals, as well as helping individuals navigate the process⁵. The care navigation role is widely recognised as crucial in other jurisdictions and several such positions have been funded by government in other Australian States.

Submissions underscored the critical importance of the Care Navigator Service and articulated why this is of particular relevance in the context of VAD.

“Dying people may be at the limit of their mental, physical and economic resources and find it difficult to locate factual VAD information and health professionals who can assist them with VAD-related matters. This is particularly true for individuals in aged care or palliative care facilities, where patients are entirely dependent on visiting medical practitioners and health professionals. Care navigators are, therefore, a critical part of the system to ensure that people have the right to access VAD if they wish. The APS strongly advocates for similar patient-centred and coordinated care navigator services to also be adopted in the NT alongside VAD legislation.”

– Australian Psychological Society, Submission 36

The Panel heard widespread and resounding support for the establishment of a VAD Care Navigator Service in the NT.

“We support the employment of a VAD Navigator to provide support to patients, families and also clinicians.”
– Heads of Departments, Alice Springs Hospital, Submission 80

“VAD navigators are a great support for assisting those in understanding the process of VAD.”
– Katherine hospital consultation

The Panel heard from those who thought a Care Navigator Service could specifically assist with the needs of culturally and linguistically diverse individuals, Aboriginal people, members of vulnerable population groups, and those living in rural and remote areas. Given the unique cultural context of the NT, it was emphasized the Care Navigator role should be carefully planned and implemented, involving thorough consultation with Aboriginal people, multicultural agencies, and faith communities. Appropriate cultural knowledge and training was seen as an essential component of training and accreditation to undertake work within the Care Navigator Service.

⁵ Downie, J, *Medical Assistance in dying: Lessons for Australia from Canada* (2017), QUT Law Review, 17(1):pp. 127-146.

In addition, the Panel heard there is a need to include those with cultural knowledge as part of the Care Navigator Service.

“A clear pathway should be identified to assist health providers navigate appropriate consultation/cultural ceremonial requirements.” – Survey response

The Panel heard adequate resources should be allocated to the Care Navigator Service. This is especially crucial for providing outreach and services in rural or remote areas. Care Navigators should be readily available wherever their services are required. In Victoria, in response to feedback, the Victorian VAD Care Navigator Service was extended to cover regional Victoria, with extra Care Navigators appointed, allowing care to be delivered closer to home.

Ensuring the well-being of the health care staff is a critical component of a VAD Care Navigator Service. It is paramount to maintaining quality patient care and fostering a sustainable and positive work environment. Providing adequate support, resources, and opportunities for self-care can help address some of the complexities of providing VAD services. In other jurisdictions, the Care Navigator Service has formed a Community of Practice during early implementation for health care personnel involved in VAD. This initiative aims to facilitate the exchange of experiences, lessons, and mutual support among participants.

Pharmacy service

The Panel identified a range of additional issues associated with ensuring appropriate substance safety, supply, storage and disposal in the NT context. The geographical complexities involved in supporting multiple pharmacy services to comply with any relevant legislative functions and requirements poses significant practical challenges. It is considered that a centralised Pharmacy Service would be the most expedient solution to ensuring community safeguards, aligning with other jurisdictions in Australia.

Co-locating Care Navigator and Pharmacy services enables information and resource sharing and builds capacity as well as peer support.

Under the Panel’s proposed model, the centralised Pharmacy Service would be the sole supplier of Substances. Pharmacists employed within this service would be required to complete accredited VAD training to be eligible to perform functions assigned to pharmacists by the relevant VAD legislation.

It is the view of the Panel that this would address the practical implementation concerns raised during the consultation process and ensure rigorous compliance with legislative provisions related to the safe delivery, management and disposal of Substances.

“Lessons from pharmacy colleagues in other jurisdictions where VAD is available have been to ensure pharmacists are integrated and embedded within the VAD care team and decision-making process[es] rather than acting as a stand-alone distribution service. This type of integrated service model assists with communications between health care professionals, patients and family as well as ensuring timeliness of access to appropriate medications. Early engagement of pharmacists also ensures consideration of appropriate storage, administration delivery and return (where appropriate) of these medicines.”
- A/Prof Bhavini Patel, NT Health Medicines Management, Submission 87

Notably, the Panel did not receive any submissions during the consultation period from private practice pharmacists stating their views on participating in VAD.

A centralised Pharmacy Service would be responsible for procuring and dispensing all prescriptions of VAD substances. This process would streamline the supply processes and align with the experiences in other Australian States:



- Supply the substance directly to the eligible person (or nominated contact person).
- Provide education around the administration of the substance.
- Support safe storage and return of the VAD substance (in the event of death preceding use or any unused portion).
- Advice and support with Medical practitioners in the prescription, administration and return of unused substance.
- Provide a disposal service for any unused substances.
- Ensure appropriate compliance with other relevant legislation (including the *Medicines, Poisons and Therapeutic Goods Act 2012*), Schedule 8 Code of Practice and labelling requirements.

In a similarly small jurisdiction in Tasmania, the VAD Pharmacy Service during the 2022-2023 period received only 42 prescriptions for a VAD substance, dispensed 35 VAD substances and disposed of 12 VAD substances⁶. It is unlikely full-time employed staff would be required and a centralised model in a small jurisdiction like the NT would practically allow suitably trained and accredited pharmacists to be called in as required.

As with other health care providers involved in a centralised model, the centralised Pharmacy Service would reduce the likelihood of conscientious objections from pharmacists who would otherwise receive a request for dispensation of a VAD substance under a community based model and reduces the prospect of delays or obstructions due to the unavailability of a qualified pharmacist to participate in the process.

CONCLUSION

Implementing a centralised VAD service model, which comprises co-located assessing and coordination practitioners, care navigator services and pharmacy services, provides a unique opportunity and solution to many of the challenges that may otherwise be encountered with a community based model of VAD services in the NT.

RECOMMENDATION 2

The NT should develop and fund a single, centralised service for the delivery of VAD. This should include VAD practitioners, pharmacists and care navigators.

Due to the very specific cultural safety concerns related to provision of VAD, the service should be stand-alone, and clearly separate from existing NT Health facilities.

2.2. VAD Practitioners

VAD practitioners fulfil three distinct and essential roles: coordinating and consulting practitioners responsible for assessing patient eligibility, and administering practitioners in charge of administering VAD substances.

Across all Australian States, coordinating and consulting practitioners are required to be medical practitioners, with the new ACT legislation permitting one of these roles to be undertaken by nurse practitioners. While most States, including WA, Tasmania, Queensland and NSW, authorise appropriately trained nurse practitioners to act as administering practitioners, this is not the case in Victoria. While there is universal acceptance that an initial assessment must be undertaken by a medical practitioner who has a minimum level of specialisation and experience, the benchmark for that level of training and experience varies from jurisdiction to jurisdiction. This is detailed in the following section.

The Panel acknowledges that there needs to be a minimum standard of qualification and experience to ensure the requisite skills and expertise to deliver VAD safely. However, it is important that these requirements are not overly prescriptive and create unnecessary barriers to those persons seeking VAD assessment. Within the NT context, accessibility is potentially severely limited by a paucity of specialist medical practitioners. Concerns were raised that an overly prescriptive minimum qualification and experience requirement may have the practical effect of restricting access to VAD to the Darwin region due to the limited number of eligible medical practitioners in the regions. The Dying with Dignity submission (#69) to the Panel identified the challenges in the Victorian experience of the burden on persons living in regional and rural areas accessing a specialist to assess eligibility was considered to amplify the difficulties of those in the NT.

Other States have identified that general clinical training as a medical practitioner is not the only, or necessarily best, qualification requirement for those involved in assessing, approving or administering VAD services. Consultations with the NT Chief Medical Officer identified the most appropriate measure of eligibility to practice in VAD services is subject matter accreditation rather than medical specialisation. In line with requiring suitable qualifications and experience to undertake VAD assessments, the Royal Australasian College of Physicians (RACP) submitted (#74) that:

“Proposals could consider setting out the domains of expertise required to provide voluntary assisted dying, rather than restricting it to a particular profession or qualification level, which could create barriers to access...” Page 34 VAD Final Report 2024

Additionally, concerns regarding medical errors and lack of qualifications and experience with respect to prognosis and diagnosis were raised, reinforcing the need to ensure appropriate clinical experience. It is further acknowledged in the RACP submission:

“Participating practitioners would also have to be properly skilled in a number of domains and would have to be qualified in the diagnosis and prognosis of the specific medical condition(s) presenting in each person requesting assistance in dying”.

A diversity of views of the relevant qualifications and experience of assessing practitioners were expressed in written submissions during the consultation phase, including having more than one assessment.

“Multi-Professional requirement – more than one medical professional, including Doctors and Nurse practitioners should be mandated to assess a person requesting assisted suicide.”
– Australian Christian Lobby, Submission 54

A number of people raised the idea that assessments would ideally be undertaken by those with a pre-existing therapeutic relationship with the patient, for example, in the Australian Care Alliance submission.



"The lack of ability for physicians who are actively caring for terminally ill cancer patients to accurately assess their decision-making capacity is likely to be worse in doctors who do not have an established relationship with the person before assessing a request for... 'Voluntary assisted dying.'"
- Australian Care Alliance, Submission 18"

Regarding capacity assessment for patients requesting VAD, the Royal Australian New Zealand College of Psychiatrists provided a submission (#58) which stated:

The RANZCP considers that capacity assessments for VAD should only be conducted by medical practitioners (doctors) with specialty training in this area. This requirement also applies to psychiatrists – while psychiatrists do routinely perform capacity assessment for other purposes, capacity assessment for VAD is complex and has specific requirements.

Although not supporting VAD, if introduced Dr Phillip Carson (Submission 2) suggests:

"There should be at least two medical opinions regarding the prognosis of terminal illness. One from a GP who has the longest relationship with the patient and the other from another specialist with qualifications in the field of the patient's terminal illness. A third independent mental health opinion from an appropriately qualified practitioner if either of the primary certifying doctors suspected untreated depression or other mental illness."

Many respondents identified a further challenge in the assessment of eligibility for Aboriginal people, given cultural and language challenges that may exist. A participant at the meeting of Aboriginal Liaison Officers at Alice Springs Hospital wondered if there needs to be particular ways to assess if Aboriginal people are "not thinking straight", recognising that "not thinking straight" is common as people approach the end-of-life.

Within NT Health, there were a range of opinions garnered from direct consultations with medical practitioners at Alice Springs Hospital and Royal Darwin Hospital. These included minimum standards of specialist medical practitioners or senior unsupervised medical staff to junior medical practitioners in early post-graduate training voicing approval and willingness to support VAD assessment processes.

Comparative qualification and experience requirements

The Panel notes there has been an evolving minimum standard of qualification and experience as States have implemented their respective VAD legislation. The table below provides a comparison of the qualification and experience requirements in each other Australian state and territory.

The ACT legislation allows nurse practitioners as 'Coordinating' (Initial Assessment) and 'Consulting' (Second Assessment) Practitioners. However, at least one of the assessments must be undertaken by a medical practitioner holding specialist registration for a minimum period of one year. There is no requirement for medical practitioners to hold specialist expertise in the person's medical condition. Eligible nurse practitioners must have relevant and appropriate experience to undertake the VAD assessment.



	VIC	WA	TAS	SA	QLD	NSW	ACT
Start date	19 June 2019	1 July 2021	23 October 2022	31 January 2023	1 January 2023	28 Nov 2023	N/A at time of print
Specialist Registration	5 Years	1 Year	5 Years	5 Years	1 Year	No minimum	1 Year
General Registration	Not Permitted	10 Years	Not Permitted	Not Permitted	5 Years	10 Years	Not Permitted
Nurse practitioner	Not Permitted	Not Permitted	Not Permitted	Not Permitted	Not Permitted	Not Permitted	1 Year
Overseas Trained Specialist (provision registration)	X	✓	X	X	✓	X	X
Mandatory training before assessing	✓	✓	✓	✓	✓	✓	✓
Conflict of Interest	X	✓	✓	✓	✓	✓	✓

With the exception of Victoria, each State precludes medical practitioners from participating in VAD processes with family members, or where there is a conflict of interest in which they stand to benefit. All States have a mandatory training requirement which must be completed prior to being involved as Coordinating and Consulting Practitioner.

The requirement for a practitioner to be a specialist in a specific disease, illness or medical condition creates an artificial barrier to access to VAD and this conception fails to acknowledge the skills and experiences that many practitioners in regional, rural and remote locations have developed over time in managing life-limiting conditions.



Coordinating or Consulting Practitioners

The Panel sought views regarding the suitability of other health professionals, such as nurses, participating in the VAD assessment processes.

Several submissions supported an expansion of suitably qualified and experienced practitioners to include nurses.

"...[ALA] supports the involvement of suitably qualified nurse practitioners to participate in the NT's VAD Scheme, if they otherwise meet any training or other requirements, especially if it would enable access to VAD for persons living in regional, rural and remote areas."

– Australian Lawyers Alliance, Submission 50

"...appropriately qualified and experienced nurse practitioners as assessing practitioners in the VAD process should not compromise the safety of VAD. All practitioners who may have a role in VAD request and assessment process must be suitably qualified, and legislation would contain a requirement to refer a person for additional assessment if the assessor is unable to make a determination about a person's eligibility."

– Australian Centre for Health law Research, QUT, Submission 41

"...allowing nurse practitioners to act as both VAD assessors and providers seems appropriate to ensure equitable access to VAD in the NT."

– Dr Kerstin Braun Associate Professor (Law) UNISQ, Submission 75

"To ensure timely access VAD and as far as possible equity of access to VAD in remote communities, we recommend that any VAD law approve the use of suitably trained and experienced nurse practitioners to undertake assessment of applicants for VAD and to administer VAD medication."

– Clem Jones Group, Submission 15

The Panel notes that broadening the scope of health practitioners in the assessment process with the inclusion of nurse practitioners may present difficulties due to the low availability of suitably qualified nurse practitioners in the NT compared with other jurisdictions. Given the nature of VAD, 'relevant experience' provisions would require consideration of minimum standard of practice in end-of-life care.

The Panel has carefully considered and weighed the evidence of other Australian jurisdictions with VAD legislation. It is acknowledged that overly prescriptive requirements for specialist registration will severely hinder access due to the legislative requirements for face-to-face assessments. There is a need to strike a balance between equity and access to VAD in the NT context, while ensuring there are appropriate safeguards. The unique composition of our population and cultural safety must be considered in the development of safeguards to ensure only suitably qualified health professionals are involved in the assessment process, as either a Coordinating (Initial Assessment) or a Consulting (Second Assessment) Practitioner.

The Panel concluded that in the NT, Coordinating and Consulting Practitioners should be qualified medical practitioners with at least five years registration, or one year of specialist registration.

Administering Practitioners

The third category of health practitioner involved in the VAD process is the Administering Practitioner. Where an eligible person chooses to have a substance administered by a health practitioner rather than self-administration, the substance is dispensed to the Administering Practitioner. In many cases the Coordinating Practitioner would also be the Administering Practitioner. However in other States, legislation separately provides for the role of the



Administering Practitioner. This allows some additional flexibility in the process and alleviates the potential strain on medical practitioners who are willing to undertake the function of Coordinating Practitioner for patients but may be adversely impacted by participating in administration of the VAD substance in every case. When the Administering Practitioner is a different person to the Coordinating Practitioner, the Administering Practitioner will have obligations to ensure that they are satisfied that all preceding steps in the process have been met.

The Panel's consultations included paramedics and ambulance services in the NT. In the course of consultations, individual paramedics expressed a willingness to participate in VAD services including as Administering Practitioners provided that appropriate training and supports were provided under any future legislation. Some paramedics shared with the Panel their experiences of encountering situations as first responders in which people have died by accident as well as intentionally. In that context, they expressed a desire for VAD legislation to provide people with a lawful and dignified alternative to alleviate intolerable suffering.

Mandatory training

The Panel consulted widely with health practitioners in the Territory, as well as interstate colleagues around training for VAD practitioners. Practitioners must undergo mandatory training in other jurisdictions before being able to provide VAD services. The Panel heard repeatedly during consultations that providing education, training and support to all health care professionals engaged in VAD is vital during the implementation stage.

"Training is paramount"

– Survey response

"Stringent checks & balances related to assessment, training and accreditation of medical professionals should underpin the ethics & practicalities of VAD."

– Survey response

The content and format of training differs between Australian States. At a minimum, the training covers legal and compliance aspects related to VAD⁷. While these aspects are covered by training in other jurisdictions, the training has been criticised for a number of reasons. Doctors and nurse practitioners have stated they perceive the training as time-consuming, overly focused on legal and bureaucratic aspects of VAD processes, and lacking in the ethical content necessary for health professionals to navigate the complex challenges inherent in the VAD process. While some States have made efforts to offer clinical skills training, including procedural training, there has been a need expressed for more training in areas such as communication with patients and their families, and grief and bereavement support. The Panel has heard of a strong desire for clinical and communications skills training. Furthermore, subject to legislative reform, training in telehealth assessments has been identified as an area of need.

Specific examples from consultation include the following:

"All health care professionals play a vital role in the delivery of end-of-life care. The MMT supports the formation of a specific VAD team rather than relying on single service models. These dedicated teams of health care professionals should have the ability to be stood up as required and have the appropriate training to deliver empathetic and culturally safe service to all Territorians."

– Medicines Management Team, Submission 87

⁷ Willmott L, Feeney R, Yates P, Parker M, Waller K, White BP. A cross-sectional study of the first two years of mandatory training for doctors participating in voluntary assisted dying. *Palliative and Supportive Care*. Published online 2022:1-7. doi:10.1017/S1478951522000931

"Staff should be provided the necessary training (not only doctors for administration but other hospital staff such as nurses, in terms of how to navigate such events involving patients and their families)."

– Survey response

"Needs specific training – it is a lot different to normal clinical work, and there would need to be screening for compassion fatigue."

– Alice Springs Hospital Open Forum

The Panel also acknowledges cultural safety training is crucial for VAD practitioners in the NT due to the region's diverse cultural landscape, which includes a significant Aboriginal population with specific beliefs and practices surrounding end-of-life care. Such training ensures practitioners can provide respectful and sensitive care that honours cultural differences, fosters trust, and addresses the unique needs and perspectives of all patients. By understanding and integrating cultural considerations, VAD practitioners can improve communication, support informed decision making, and enhance the overall quality of care for all individuals in the NT.

"Given the complexity of cultures and languages of NT populations, AMA NT considers such a properly funded credentialing process to allow such VAD practitioners in the NT"

– AMA NT, Submission 11

"The NT is unique amongst Australian jurisdictions in having a very high proportion of Aboriginal citizens, many of whom live in remote areas with a strong traditional culture, language and family networks but limited formal English and education. Any decision regarding the introduction of VAD in the NT and its potential processes must take account of these facts. Accordingly, Aboriginal communities and organisations must be involved in the[ir] design"

– Congress, Submission 88

The Panel supported the conclusions drawn from the consultation and concurred with that notion training should encompass more than compliance and understanding of the functions of the legislation. It noted the substantial progress made in other jurisdictions towards creating comprehensive training modules, which could serve as a suitable model for developing training in the NT⁸.

The Panel received a number of responses to the effect that all VAD practitioners should be required to undertake mandatory training before providing VAD services. However, there was also interest in offering training to a broader range of health professionals. For example, other Australian jurisdictions, such as Tasmania and New South Wales, have developed a short 'VAD awareness module', with an audience of any health care profession⁹. VAD education is also being offered through medical schools.

Barriers to completing mandatory training were identified through discussion with interstate VAD practitioners. These include its often unpaid nature and the absence of recognition for Continuing Medical Education (CME) credits. This discourages potential practitioners from pursuing training, resulting in a small number of VAD practitioners handling a high volume of requests, which in turn increases the risk of burnout. Distributing the workload among more trained clinicians would benefit individuals and promote sustainable service delivery. Strategies to incentivise training include making it eligible for CME points, providing dedicated non-clinical training time, and securing appropriate funding.

8 White BP, Willmott L, Close E, et al. Development of VAD Training in Victoria, Australia: A Model for Consideration. *Journal of Palliative Care*. 2021;36(3):162-167. doi:10.1177/0825859720946897

9 <https://www.health.nsw.gov.au/voluntary-assisted-dying/Pages/general-awareness-training.aspx>
<https://www.health.tas.gov.au/health-topics/voluntary-assisted-dying/training-voluntary-assisted-dying>

*"Expertise and training for health care practitioners on VAD is essential...
This will need to be adequately funded"–*
- The Royal Australasian College of Physicians, Submission (#74)

In Tasmania, VAD training has received accreditation from both the Australian College of Rural and Remote Medicine and the Royal Australian College of General Practitioners.

The Panel would support VAD training being accredited for CME credits.

RECOMMENDATION 3

VAD assessments must be conducted by appropriately trained medical practitioners only.

VAD practitioners must undergo mandatory training and hold appropriate qualifications



Conscientious objection

The Panel acknowledges health professionals have the right to not be compelled to participate in voluntary assisted dying. This personal objection may be for many reasons but is acknowledged as a conscientious objection. All VAD legislation in Australia provides an express recognition of the right of conscientious objection by health care providers to participation in VAD.

The Panel noted the different positions taken by numerous health professionals, particularly those who object to VAD and are against having a consultation with patients at all. Overall there was a strong view from the majority of Territorians that a referral to another practitioner who supported VAD was considered to be the best approach. The community clearly demonstrated the expectation that patient referral to a practitioner or service that has no objection to VAD was important.

Some submissions emphasised that while practitioners should not be forced to undertake actions that are not consistent with their beliefs, they will bear some responsibility to the patient for referral. A number of responses suggested having information readily available in all health services and waiting rooms where a central information source could assist with access. However, the Panel also heard VAD is an extremely sensitive topic which does not lend itself to published information being left on display in waiting rooms. The Panel did not consider that a requirement to make information available in that way was an appropriate response to conscientious objection by medical practitioners to participating in VAD.

The Panel also noted that from the perspective of medical ethics, the question of whether VAD is a 'treatment option' remains unsettled and therefore a medical practitioner with a conscientious objection to VAD may not be ethically obliged to inform a person about the option of VAD.

The Panel resolved that if a centralised model for VAD were adopted in the NT, every request by a patient for VAD would be referred to the centralised VAD service in any event. On balance, the Panel considered in that context, the imposition on medical practitioners, even those with a conscientious objection, to simply pass on information to a patient about the centralised VAD service would not amount to an undue interference with their conscientious objection to VAD.

Residential facilities must not hinder permanent residents from accessing VAD on site

The Panel heard many views on whether residential facilities should be able to object to providing VAD services. In New South Wales and South Australia, residential facilities can decide whether to provide VAD services and what support they offer to residents seeking VAD. However, those that choose not to provide VAD services still have legal obligations to enable residents to access VAD if they wish.

In general, the Panel heard from older Territorians that respecting residents' dignity and supporting their end-of-life choices is crucial for delivering optimal person-centred care, and that facilities' values and beliefs should not impede a person's right to access lawful treatments or negatively impact a resident's dignity and right to choose. The following survey responses illustrate this:

"Health or aged care facilities should not be allowed to inhibit a person's access to voluntary assisted dying. It's a human right to access any health services & this should always be person centred. Individual workers can decline participation at a facility but allow access to patients by willing practitioners. Don't make terminally ill people travel to access VAD."



“The thin markets of NT aged care mean that consumers may have little choice of the facilities in which they reside, and for this reason care facilities should be prohibited from opting out of providing access to VAD on site. It is also for this reason that self-administered and home-based assisted options should be available.”

“Where you live must not dictate access (or inaccess(sic) to) to VAD services.”

“I believe the person must be able to decide where this will happen i.e. home, aged care home, hospital.”

VAD laws in South Australia, New South Wales and Queensland impose specific legal obligations regarding VAD on such institutions. All facilities must allow residents to receive information about VAD upon request, including allowing a medical practitioner to visit the facility to provide information and provide a VAD service. VAD laws in Victoria, Western Australia and Tasmania do not discuss residential facilities' participation in VAD.

Some jurisdictions require facilities that do not provide VAD services to inform all residents, families, and the public by publishing this information, such as on the facility's website, to enable prospective residents to make informed decisions. If a resident requests VAD, the facility should inform them as soon as possible that they do not provide VAD.

The Panel agrees residential facilities should be required not to hinder permanent residents from accessing VAD on site, and should allow requests, assessments and administration of VAD for residents who wish to undergo VAD.

RECOMMENDATION 4

Health professionals should be allowed to conscientiously object to participating in any VAD framework under NT legislation.

Conscientious objectors should be required to inform requesting patients of VAD services.

Residential Facilities may not hinder permanent residents from accessing VAD on site.



2.3. Interpreters

Given the subject matter of VAD, it is critical the assessing practitioner consider whether an interpreter may be required.

In other States, VAD legislation contains specific requirements for when an interpreter is necessary. The medical practitioner who undertakes the initial assessment must determine whether an interpreter is necessary. If an interpreter was used in the initial request or assessment, the medical practitioner is required to record that fact on the assessment form which is submitted to the Review Board.

The Panel learned that established criteria, rules/roles and responsibilities, qualifications and other relevant standards apply to interpreters providing interpreter services related to VAD. Interpreters must be accredited by the National Accreditation Authority for Translators and Interpreters or Speech Pathology. In other jurisdictions, the Review Board specifies the training requirements which must be undertaken by eligible interpreters. The interpreter is required to independently certify the request is made by a person with capacity who understands the information that they have been provided with.

The Panel supports the inclusion of a requirement that at each stage of the assessment and administration process where an interpreter is required, that fact should be documented and the interpreter should certify their participation accordingly.

Access to qualified and culturally appropriate interpreters is vital. Using family members is not an ideal option as they may not be dispassionate about or unaffected by the information being conveyed. Language services have also repeatedly informed health practitioners that assessments with people from culturally and linguistically diverse backgrounds may require longer consultations to enable translation to occur.

Challenges already arise in the use of interpreters for Aboriginal Territorians. The Panel experienced such challenges first-hand when it undertook consultation within Aboriginal communities with the assistance of interpreters. There are two key issues that arise from the use of interpreters for Aboriginal people: First, the subject matter of death and dying carries enormous cultural sensitivity in some groups and as a result, an interpreter may be prevented from discussing the subject matter for cultural reasons which are often poorly understood by others. Secondly, it is often the case that a person who is able to interpret in a specific Aboriginal language is able to do so because of kinship ties to people within that language group. As a result, there is a high probability that the person interpreting has a pre-existing family or kinship relationship with the person being interpreted for. Those relationships may involve broader cultural obligations, responsibilities or boundaries which are poorly understood by others.

Given the critical subject matter of the decision under discussion, the Panel considers that it is not possible to set up in advance a system for Aboriginal interpreting of VAD decision making that will be appropriate in all settings. Mindful of the very low likelihood of interest in VAD amongst the Aboriginal population for whom such kinship and language ties are most significant, the Panel considered that the development of appropriate interpreter safeguards and protocols should occur incrementally under the supervision of the Review Board, initially on a needs basis and subject to careful ongoing review.

The effectiveness and use of interpreters should be made the subject of the review of the Act. To that end, the Review Board should collect and analyse data relating to the use of interpreters in VAD from the commencement of implementation.

RECOMMENDATION 5

Interpreters must be accredited in order to provide interpreter services in VAD.

At every stage of the VAD processes, where an interpreter is used, their involvement should be documented and the interpreter should certify their participation accordingly.

2.4. Clinical guidelines

The Panel heard from many health care practitioners that certain aspects of VAD should not form part of VAD legislation, as they are already part of good clinical practice. One instance illustrating this scenario is the dilemma encountered when determining the eligibility of a patient for VAD in cases where there are concerns regarding their decision-making capacity assessment.

Some VAD legislation mandates that health care practitioners refer such cases to specialists for further evaluation. However, referral in such cases to neuropsychologists, psychiatrists, or geriatricians is already customary within good clinical practice. The Panel concluded the response of an assessing practitioner in cases of uncertainty should be left as a matter for professional clinical judgment rather than imposing legislative mandates. Where an assessing practitioner is unable to be satisfied as to eligibility of a patient, even after consultation with colleagues, the appropriate clinical response would be to assess the patient as ineligible.

Other Australian jurisdictions also have clinical guidelines relating to VAD in their jurisdictions.

Establishing clinical guidelines in the NT is important in ensuring health care professionals have a comprehensive understanding of VAD and their responsibilities under a legislative framework. The guidelines would serve as a roadmap, addressing critical questions and areas of uncertainty for health professionals who may care for VAD patients.

Clinical guidelines should be developed and approved by the CEO of NT Health. The application of clinical guidelines and any areas for improvement or necessary alteration are matters which the Review Board would be empowered to consider.

Components could include delineating roles and responsibilities in VAD, clarifying the process for requesting VAD, outlining eligibility criteria and assessment procedures, and detailing the prescription, supply, and administration of VAD substance. The guidelines would outline the roles and responsibilities of the proposed pharmacy and care navigator services and provide their contact details. They should also point clinicians towards appropriate training and resources.

Development of clinical guidelines provides a further opportunity to collaborate with Aboriginal organisations to ensure cultural appropriateness and safety in the NT context. This would ensure the guidelines are relevant, accessible, and respectful of Aboriginal values and beliefs surrounding end-of-life care. Additionally, engaging Aboriginal communities in the development process will foster trust, promote inclusivity, and enhance the effectiveness of the guidelines in addressing the diverse needs of all individuals seeking VAD services in the NT.



2.5. Organ donation

Organ donation was not a major focus during consultations but it was touched upon briefly. Where mentioned, it was generally health professionals wanting to ascertain whether VAD patients would be eligible to donate organs. Regarding community opinion, one survey respondent stated that:

"I would like to see that within the mandated applications for VAD, a section on organ and tissue donation. Those people applying can consider the opportunity to be an organ/ tissue donor at death. If a person says yes then a mandated referral to the DonateLife NT team which is part of NT Health would be made to provide the person and their loved ones with further information and appropriate testing."

In 2023, Australia became the fifth country globally to enable organ donation after voluntary assisted dying, after a Victorian woman successfully donated organs. A handful of patients have also consented to eye or tissue donation, which is a separate process. There are no laws against organ donation for VAD patients, and Belgium, Netherlands, Canada, and Spain have programs that allow for donation after VAD. About 300 people globally have donated organs after VAD, leading to around 1,000 additional individuals undergoing life-saving transplants. In Canada, six per cent of total organ donor numbers came from those who chose Medical Assistance in Dying – their term for VAD – in 2021, the highest per centage internationally.

To enable organ donation, the international practice is that the death must occur in hospital and the substance must be intravenously administered. Patients choosing VAD often prefer home deaths or self-administration, precluding organ donation. Many patients who undergo VAD have advanced stage cancer, and these individuals are not eligible for organ donation, however they may still donate tissues or eyes. Patients with conditions such as motor neurone disease and some cardiovascular or respiratory disease may be eligible to donate organs. If eligible, patients must consent to organ donation. Organ donation is usually a process facilitated by DonateLife clinicians.

All States that currently allow VAD are investigating possibilities to allow donation after VAD and current legislation does not specifically mention or prohibit organ donation. Collaboration among Australian jurisdictions on VAD and organ donation is ongoing.



2.6. Contraventions and offences

VAD legislation throughout Australia includes a range of obligations and prohibitions which, together, provide essential safeguards to ensure compliance with all aspects of the VAD process. Confidence in the safe and appropriate provision of VAD services will depend on being able to demonstrate that the Act is strictly complied with on pain of heavy penalties on the rare occasions that it is not.

Legislation differentiates between some acts and omissions which constitute criminal offences and attract penalties including risk of imprisonment. Examples include inducing or coercing a person to seek VAD, or administering a substance to a person intending to cause their death, other than strictly in compliance with the Act. Understandably, the offence of administering a substance intending to cause death knowing that it is not authorised under the Act carries a maximum penalty of life imprisonment.

Other, less serious contraventions of the Act, particularly as to time frames for submitting documentation to the Review Board or record keeping, are treated as regulatory offences attracting a fine and may also constitute disciplinary breaches which may lead to action for professional misconduct against health practitioners.

The Panel considered that the imposition of heavy criminal sanctions together with appropriately weighted punishments for lesser contraventions of the Act provide the necessary balance and safeguards to ensure compliance with the Act. The Panel was made aware of at least one matter in which a medical practitioner failed to correctly complete a patient's declaration of seeking access to VAD. The patient's declaration had not been signed by two witnesses and subsequent declarations by the practitioner to the effect that the declaration was compliant were therefore incorrect. The practitioner was found to have engaged in professional misconduct, was reprimanded and fined \$12,000 under the Health Practitioner National Law.

The Panel did not consider it necessary to make a specific recommendation in relation to Contraventions and Offences under any proposed VAD law for the NT but observes that they are an essential part of ensuring adequate safeguards for compliance with the Act.

2.7. Indemnities

Equally importantly, VAD legislation also contains express provisions indemnifying health practitioners and others who participate in VAD processes under the Act in good faith from any liability, either civil or criminal. The reassurance that well intentioned actions receive the protection of the law is vital to ensuring the willingness of health practitioners to participate in providing VAD services. In addition, roles such as the Contact Person for a person seeking self-administration, and which carry significant responsibilities relating to possession, supply, storage and disposal of VAD substances could not be undertaken without the benefit of such legal protections.

It is necessary to ensure that VAD legislation makes express provision to release health professionals and paramedics from their obligation to administer life-saving or life sustaining treatment to a person who has accessed VAD.

The Panel did not consider it necessary to make a specific recommendation in relation to indemnifying participants in VAD processes but observes that they are an essential part of ensuring the practical workability of VAD legislation.



03

VIEWS ON VAD



3. Views on VAD

VAD has been a longstanding and contentious issue globally, including in the NT. Debates are often sharply divided between supporters and opponents of legal reforms. Various philosophical and ethical viewpoints surround the topic.

Advocates for VAD emphasise autonomy, alleviating suffering and addressing concerns about unregulated practices and suicides. They argue that assisted dying aligns ethically with existing practices such as treatment refusal and reflects public sentiment.

Opponents voice concerns about vulnerable individuals and the potential expansion of criteria over time, asserting that VAD undermines the value of life and medical ethics. They also worry about its impact on health care providers and the support for palliative care, seen as more suitable for addressing complex end-of-life needs. The Panel collected a broad spectrum of Territorians' perspectives on VAD, outlined below.

3.1. Support for VAD

The Panel heard from those who supported VAD. Arguments in favour of VAD stressed the importance of an individual's right to choose and the relief of intolerable suffering. There were Territorians that also raised issues related to existing unregulated VAD taking place regardless of legislation and VAD avoiding suicides.

"I feel very strongly in support of VAD. People should be entitled, particularly in old age and poor health (and not necessarily terminal illness) to choose VAD. Too many old or seriously unwell people with a terrible quality of life are forced to suffer and/or lose their dignity. It is wrong that their best alternative is suicide, which can be traumatic for them, and their loved ones."

– Survey response

"You only need to watch one person die in excruciating pain from a terminal illness to want to support this. I'm strongly supportive of VAD and believe it will make a positive difference in many families' lives."

– Survey response

The Panel received a large number of submissions detailing personal experiences that informed Territorians' views on VAD. The perspectives that these experiences provide are important and appreciated by the Panel, especially as sharing these experiences can cause considerable distress. Some examples are included below, though not all submissions that detail personal experiences are included here.

"My father has now been living in hospital for over a year, anxious, delusional, having to be chemically restrained on occasion, wheelchair-bound, switching between dad and an unrecognisable person, living with lewy body dementia. My dad is a proud, generous and kind Territorian, entrepreneur, miner, cattleman and family man, who made it known he wanted to be shot if he lost his mind (!) He has lost his mind, there is nowhere for him to go, so he remains in hospital... Please, bring in VAD, include dementia and hurry up"

– personal account

"I think as much choice as possible should be given to the person. They should be able to do it where, when and how they want. If they are competent now, but want to access VAD some time far in the future when they may not be competent they should be allowed to choose this."

– personal account

"... just knowing that we did actually do what he wanted and he did it with a lot of dignity and his contact person in the tuxedo and champagne, that's sort of a nice thing. If I wasn't involved, it would have never happened and he would have died a miserable, long, prolonged death in hospital. So that's a lot of reward."

– personal account

The Panel would like to extend its gratitude to those who shared their own experiences, or the experiences of their loved ones.

3.2. Opposition to VAD

The Panel has learned there are a range of reasons why practitioners and others in the Territory community object to participation in voluntary assisted dying. They can be secular, humanist, professional, cultural and/or religious. The concerns are as broad as the reasons supporting VAD.

The Panel heard from numerous health practitioners including general practitioners who are living and working remotely in the NT, who believe there is fear in their respective communities about VAD therefore they are reluctant to be part of the process because of the possible damage to their patient relationships and the ongoing viability of their clinics. It should be noted they stressed that relationships can take a long time to recover from damage and then take even longer to restore¹⁰.

The Panel also met with traditional owners and local Aboriginal leaders and heard their concerns about new laws that could be detrimental to upholding their traditional laws and dying processes¹¹.

At community consultations, some Elders told the Panel: “VAD is not acceptable”, “We have our own laws that have stood the test of time for tens of thousands of years and we do not need to change them now”, “There has always been fear in our community about going into hospital or going to Darwin when you are sick, because you will probably not return home”.

In consultations conducted in Nhulunbuy, the representations were clear that “from a cultural perspective when it comes to family dying it's not seen as appropriate for that process to be sped up in anyway because there is a ceremonial process that has to happen, a beautiful process with song and dance, the whole family is around that person and visiting to say goodbye.”

The medical profession provided the Panel with varied levels of support for VAD and those against were also clear in their opposition. Doctor B* from the Top End region gave a not uncommon account of professional considerations: “Prescribing a medicine and saying this will kill you, I really struggle with that....Doctors are trained above all to do no harm – death is the ultimate harm”, and, “I have struggled with the idea of VAD because I have undertaken my job throughout my whole career with a focus on preserving life and above all to do no harm.”

The Panel consulted with or received submissions from a number of church groups and faith based organisations opposed to VAD, including personal meetings with Bishops Gauci and Anderson from Darwin's Catholic and Anglican churches respectively and with representatives from the Australian Christian Lobby.

“While acknowledging the importance of individual autonomy, it is paramount to consider the broader societal impact of VAD legislation, particularly on the most vulnerable members of our community. Any framework for VAD must be accompanied by robust safeguards to protect against coercion, exploitation, and unintended consequences, including addressing issues of psychosocial vulnerability and ensuring equitable access to high-quality palliative care for all.”

– Catholic Darwin Diocese, Submission 90

Both Bishops advocated for better resourced palliative care and strong safeguards if VAD is to be introduced in the NT.

3.3. Aboriginal views, concerns and considerations

Almost 30 per cent of the NT's population is Aboriginal and/or Torres Strait Islander. This cohort also carries a

¹⁰ Public consultation, Heads of Departments, Alice Springs Hospital, 16 November 2023

¹¹ Nhulunbuy public consultation, 28 November 2023

significantly higher burden of disease rate than the non-Aboriginal and Torres Strait Islander population¹² (see Appendix 4)

Consultations with Aboriginal organisations and individuals and those with strong experience with Aboriginal clients (for example, remote health workers) yielded a spectrum of views.

Many of those who spoke to the Panel expressed the expectation that any and all health services and health care rights must be accessible to all Territorians, and did not oppose VAD¹³. However specific concerns about how VAD would be implemented in practice were raised by many of these contributors.

“People might engage better with health services knowing that it could be an option to come back [to Country].”

– Red Lily Health Board, consultation 23 November 2023

Some respondents provided commentary on how VAD might be, or would not be, compatible with their own cultural beliefs.

“There will be a division because some people might [not] be able to wrap their head around it....For the older generation, [who have] one foot in the Dreamtime and another foot in religion, this would probably be really difficult.”

– Gundjeihmi Aboriginal Corporation, consultation 22 November 2023

Some respondents expressed views that extensive consultation with Aboriginal people would be needed in the process of developing a VAD model appropriate for the NT. The primary cultural themes included:

- The risks created by power and knowledge imbalances that exist for both Aboriginal or Torres Strait Islander patients using health care services and practitioners, particularly in the context of language and health literacy barriers.
- The safety and feasibility of managing VAD in remote settings given the cultural and logistical challenges involved in health care provision in that context.
- Potential misunderstanding and cultural contamination of health care services that may occur due to their direct or indirect involvement in provision of VAD.

These themes were widely expressed, in many independent submissions. It is significant to note that these themes reiterate many concerns raised in consultations about VAD with Aboriginal health services in Western Australia¹⁴.

There was also a notable silence or hesitation from some communities and organisations in response to the invitation to participate. The Panel acknowledges the need for continuing discussions and engagement with Aboriginal Territorians.

Cultural security, safety and issues relevant to Voluntary Assisted Dying

¹² https://health.nt.gov.au/_data/assets/pdf_file/0011/1267184/morbidity-burden-of-disease-and-injury-in-the-northern-territory-2014-2018.pdf

¹³ For instance, in the consultation with NT Member for Mulka, Mr Yingiya Guyula.

¹⁴ MEP op cit

The focus on cultural safety for Aboriginal users of health services is an important element of cultural security, which also identifies the necessity of focusing on health care systems and processes as well as the individual behaviours of providers.

A commitment to cultural security means building a system where Aboriginal people feel safe, secure and able to participate as staff and consumers of NT Health without fear of judgement or discrimination.

There is no single source of knowledge, authority or advice on Aboriginal cultural matters. Each Aboriginal person encountering health care services must be able to have their unique needs taken into account, and the authority for determining what is culturally safe in each situation resides with them, and with their own cultural group. It follows that many cultural concerns cannot be predetermined or addressed in advance. Rather, an evolving capacity to address these issues when Aboriginal people actually use the services must be built into the VAD service's processes.

Based on the Panel's research and community consultations, several key issues were raised of VAD processes and legislation that may have significant implications for the cultural safety of many (although not all) Aboriginal people. These are issues that must be carefully considered at all stages of legislation, implementation, provision and revision of VAD in the NT.

A detailed consideration of these cultural issues is in Appendix 9.

Broadly, they include:

- intergenerational trauma and the need for trauma-aware approaches to care;
- individual versus kinship decision-making, and family involvement in care;
- language, and the role of interpreters and/or cultural brokers;
- varying cultural understandings of illness and death, its causes, and associated practices; and
- the impact of remoteness and the infrastructure present in remote communities.

The Panel's work and report must not be the final opportunity for input from Aboriginal or Torres Strait Islander people and communities into the development of VAD services in the NT.

It is proposed that in implementing VAD there are opportunities for cultural and ethical reflection to occur safely, in real time, and as needed on a case-by-case basis, with an evolving governance process founded on respect for the cultural knowledge and experience of those Aboriginal or Torres Strait Islander people who may seek access to VAD.

3.4. Palliative Care and End-of-Life Care

RECOMMENDATION 6

The process for addressing Aboriginal and Torres Strait Islander cultural safety issues needs to be designed and resourced as a core part of the operationalisation of VAD.

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- 15 Lewis S, Willmott L, White BP, La Brooy C, Komesaroff P. First Nations Perspectives in Law-Making about Voluntary Assisted Dying. (2022) JLM 1168-81.
- 17 McCallum D (2022) Law, justice, and Indigenous intergenerational trauma—a genealogy. International Journal for Crime, Justice and Social Democracy 11(3): 165-177. <https://doi.org/10.5204/ijcjsd.2121>;
- 18 Darwin, L., Vervoort, S., Vollert, E., Blustein, S. (2023). Intergenerational trauma and mental health. Canberra: Australian Institute of Health and Welfare;
- 19 Trauma - Healing - Australian Indigenous HealthInfoNet (ecu.edu.au) Accessed March 26, 2024

Palliative Care is not VAD, VAD is not Palliative Care

It is important to differentiate palliative care from voluntary assisted dying. These approaches to end-of-life care are ethically distinct practices. Palliative care commits to not intentionally hasten death, rather striving to maximise quality of life for persons with life-limiting illness and prevent suffering in the dying process. VAD is the provision of an end-of-life choice with an express goal to hasten death to avoid suffering.

Palliative care is dedicated to alleviating suffering, improving the quality of life, and supporting patients and their families through the natural course of a life-limiting illness. Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social.

Palliative care is for anyone of any age, including children, who have been diagnosed with a life-limiting illness.

Specialist palliative care, with its focus on improving quality of life, is not just involved with the last few days of life, but often provides support over weeks or months, and then continues to support families in bereavement. For many people, palliative care is a source of comfort and solace. It enables choices for patients and families about where they are cared for, and supports a dignified death. Specialist palliative care therefore requires a multidisciplinary team approach with the patient and their family's needs and wishes at the centre of all decision-making.

End-of-life care is a specific phase of the palliative care journey. Generally, end-of-life care is the last days to weeks of life. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care²⁰.

With VAD legislated in all States, and implemented in most, there is a growing recognition that the views of palliative care practitioners are in fact diverse, and the ways palliative care services are responding to patients who seek VAD are also varied. The professional society for palliative medicine opposes VAD²¹, while Palliative Care Australia takes a neutral position²².

Palliative care as a specialty, both nationally and internationally, has advocated strongly that VAD should not be considered a part of palliative care practice²³. However, legislation should ensure that people seeking VAD are advised about, and have access to, palliative care services when discussing the range of treatment options available to a person with a life-limiting illness.

It is clear to the Panel that a commitment to supporting the choice and autonomy of people who are approaching death, and responding to their suffering and distress are values shared by both palliative care and VAD proponents.

Where VAD has been introduced elsewhere in Australia, palliative care continues to be important. Deaths related to VAD in Victoria in 2022-3 made up only 0.65% of all registered deaths, and for 2021-2 in WA that proportion was 1.1%²⁴.

The availability VAD expands the range of options available to a person at the end of their life. While palliative care and VAD are different options and separate services, individual patients may choose to access both. A person who has requested VAD may be supported by palliative care services but may ultimately choose the timing of their death from voluntary assisted dying, with support for their family continuing after their death.

The Panel agrees that it is important, as was noted in the WA report²⁵, to avoid any implication that equates VAD with dying with dignity, in a way suggesting that a death with palliative care is inherently undignified.

Availability and accessibility of palliative care

20 Palliative Care Australia, 'What is palliative care', (Web page) < What is palliative care? - Palliative Care Australia>.

21 ANZSPM *Australian and New Zealand Society of Palliative Medicine Position Statement: The Practice of Euthanasia and Physician-Assisted Suicide*. Last updated: November 2021

22 Palliative Care Australia. *Position Statement - Palliative Care and VAD* Sept 2019
2019-VAD-position-statement-Final.pdf (palliativecare.org.au)

23 ANZSPM statement, IAHPC statement, PCA statement

24 VAD Review Board *Annual report 2022-2023*. Safer Care Victoria, June 2023

25 Department of Health, WA - Final report, Ministerial Expert Panel on Voluntary Assisted Dying

Territory Palliative Care (TPC) consists of two specialist palliative care services, in Darwin and Alice Springs. They provide high-quality, culturally sensitive specialist palliative care services that address the physical, psychological, social, and spiritual needs of patients with life-limiting diagnoses.

The teams are comprised of medical, nursing, and a range of allied health staff. Both services offer inpatient care, provide a consultation service to other clinicians, and provide community support to aged-care facilities, and to patients in their own homes including in rural and remote areas. Generalist palliative care is also provided in the NT by all health services, including acute care, aged care and primary care.

Given the vast size and geographic diversity of the NT, unique approaches are employed to meet the needs of those residing outside metropolitan areas. This includes outreach teams that provide specialist palliative care, though coverage in rural and remote areas remains challenging and access to specialist palliative care services remains limited for these residents. These challenges are compounded by workforce and funding shortages.

Historically, the use of medications to manage distressing symptoms in the dying phase of end-of-life care may be misinterpreted as the intentional killing of patients. Such myths and fears continue to be widespread, particularly in rural and remote settings, and for many are a barrier to accepting palliative care referral or supports. In the NT context, these concerns are often amplified for people from different cultural backgrounds, particularly Aboriginal and Torres Strait Islander people who experience significant cultural barriers to effective participation in health services. This is discussed more in the section on Aboriginal and Torres Strait Islander Views on VAD and Appendix 9.

The Panel learned from consultations with individuals and organisations, that frank discussion about withdrawal from treatment leading to a person's imminent death is a relatively recent phenomenon in Aboriginal health. In its consultations in Central Australia, Aboriginal Community Controlled Organisation 'Purple House' showed Panel members a recently produced educational film²⁶ depicting a woman who chooses to withdraw from kidney dialysis and instead return to country to spend her last days surrounded by community and family. The video produced by Purple House was an example of culturally appropriate, innovative public education about the role and significance of palliative care.

The Panel observed a noticeable level of misinformation or lack of knowledge about the nature and scope of palliative care services offered in the Territory, particularly in community forum consultations. At least some part of peoples' perceptions about death and dying, particularly in the context of dementia, included that they would inevitably become institutionalised and would not be able to access palliative care at home. The Panel concluded there is an obvious and immediate need for increased promotion and public education about the nature and scope of palliative care options.

The need for increased resourcing for palliative care options in the NT was a common theme across the Panel's consultations, both from people in support of, and opposed to, VAD. The Panel heard compelling personal accounts of people's experiences of death and dying and their interaction with TPC as part of that journey. Some participants voiced their sadness and distress that palliative care services were not available for their family members in community, and as a result, family members passed away in hospital in Darwin²⁷. A clinic based in Central Australia spoke of the difficulties in managing palliative care treatment in remote communities including the flow-on effect from a death which occurs in community particularly in areas where housing is in short supply²⁸.

A significant number of public submissions highlighted the need for increasing funding to improve access to palliative care services in the NT, noting that there are currently very limited palliative care options in remote and regional areas.

"VAD cannot be implemented without at least an equivalent investment of new resources into palliative care to ensure that people really do have a choice in their end-of-life care."

26 Reference video

27 Community consultations, Wadeye, 29 April 2023

28 Community Consultations, Tennant Creek, 9 May 2024

– Palliative Care NT, Submission 22.1

“The NT Health Palliative Care service needs to be enhanced and resourced in the first instance [before] any VAD process is implemented.”

– Catholic Diocese Darwin, Submission 90

The Panel acknowledges the strong and consistent representations for better resourcing in the area of palliative care throughout the NT community.

Each jurisdiction where VAD legislation has been introduced has focused on the future planning and investment in their palliative care services. In Western Australia, the Ministerial Expert Panel's first recommendation was that:

“People have the right to be supported in making informed decisions about their medical treatment, and should be given, in a manner they understand, and is culturally appropriate, information about medical treatment options, including comfort and palliative care. People approaching the end-of-life should be provided with high quality care, including access to specialist palliative care, to minimise their suffering and maximise their quality of life.”

In Queensland, the Expert Panel Report²⁹ noted that:

“We agree with the Parliamentary Committee that palliative care ‘needs to be adequately resourced and supported irrespective of whether VAD legislation is introduced’ and, ‘if it is introduced, it is imperative that people have the full range of options available to them so that they can make an informed choice.’

Any scheme for VAD should complement, not detract from, the provision of high quality and accessible palliative care. The resources required to ensure that any legislated scheme for VAD operates safely and compassionately should not be at the expense of palliative care services.”

The Panel shares the same view that with the introduction of VAD legislation in the NT it is vital that adequate resourcing be provided to palliative care services, particularly to allow outreach to rural and remote communities. Resourcing of VAD services in the NT should not be at the expense of palliative care services.

RECOMMENDATION 7

Recognising the importance of palliative care services in the NT:

- A person who requests VAD must be informed of all treatment options including the nature, scope and availability of palliative care services.
- Further resources should be provided to educate the community about the nature and scope of palliative care options, particularly for people who wish to remain at home.
- Palliative care services must be consistently and adequately resourced to provide specialised and holistic palliative care to patients, wherever they live in the NT and to address the gaps in those services that result in inequities in people's end-of-life options. Implementation of VAD services in the NT must be complementary to, not at the expense of, expanded palliative care resources.

29 Queensland Law Reform Commission, *A legal framework for voluntary assisted dying*, Report 79, recommendations 3.21 – 3.25, May 2021

04

ELIGIBILITY



4. Eligibility

All VAD legislation in Australia contains a prescriptive regime of eligibility criteria. While the precise language and mechanics of eligibility criteria vary slightly, they are substantially the same throughout the nation. The one point of substantive difference that has begun to emerge as each State or Territory has introduced its legislation is in the area of prognosis of a timeframe within which death from the underlying disease, illness or medical condition is likely to occur.

The Panel's approach to consideration of eligibility criteria for VAD was to broadly seek consistency with eligibility criteria common to other jurisdictions unless the circumstances in the NT require a different response.

4.1. Residency

All VAD legislation in Australia contains an eligibility requirement of residency. This requirement operates at two levels - Australian citizenship or residency and residency of the State or Territory in which the legislation operates.

Given that the NT is the last jurisdiction in Australia without VAD laws, there did not appear to the Panel to be a compelling argument for a domestic residency requirement. Academic writing on the issue of a domestic (State based) residency requirement has suggested that it could be unconstitutional. In addition, the requirement of Australian citizenship or permanent residency as provided by some legislation has thrown up difficult questions of statutory interpretation and has resulted in findings of ineligibility in tragic individual for cases.

In light of the experiences learned from the practical operation of the legislation in other jurisdictions the Panel does not see that there is a need for any greater restriction on residency than having spent a minimum period of time in Australia, and the Territory, or otherwise having a particular connection with the Territory. The Panel considers any definition of residency should be as broad as possible and a requirement that a person have ordinarily resided in Australia for two years and in the Territory for 12 months is sufficient.

Exceptions should be considered for cross-border communities and personal connections to the NT for family, cultural, or support networks.

The Panel observed that regulations or guidelines could be developed to clarify the assessment criteria for residency and any applicable exceptions.

RECOMMENDATION 8

To access VAD in the NT, a person should have ordinarily resided in Australia for two years and in the Territory for 12 months. Exceptions should apply for cross-border communities and those with personal connections to the NT, particularly in relation to family, cultural and/or support links.

30 Del Villar, K and Simpson, A, *VAD for (Some) Residents Only: Have States Infringed s 117 of the Constitution?*, [2022] Melbourne University Law Review 45(3) at 996.

31 Del Villar, K; Wilmott, L & White, B, *The Exclusion of Long-Term Australian Residents from Access to Voluntary Assisted Dying: A Critique of the 'Permanent Resident' Eligibility Criterion*, Monash University Law Review, Vol 49 No 2 at 1.

4.2. Age

All jurisdictions in Australia have a requirement that the person be 18 years of age. In the ACT, consideration was given to removing an age eligibility requirement. This view drew significant opposition and was not pursued in the final version of the Bill as introduced to the ACT Legislative Assembly.

The concept of mature minors is known and recognised in a number of health settings but in the course of consultations, its application to the context of VAD was not supported. The broad community position expressed to the Panel was that VAD should only be available to adults (people aged 18 years or older).

The Panel did not identify any compelling reason why the NT should take a different approach on the eligibility criteria based on age.

RECOMMENDATION 9

To access VAD in the NT, a person should be aged 18 years or older.

4.3. Disease and Prognosis Timeframes

Legislation across jurisdictions in Australia is relatively consistent in the disease criteria for access to VAD. All must have a serious and incurable condition that is causing intolerable suffering. Internationally, there are some countries such as the Netherlands where the definition is broader and does not include the requirement for the patient to be in the end stage of life, rather it allows for inclusion of those for whom their illness is causing intolerable suffering from illness or accident, whether or not it is a terminal condition with a defined prognosis of death within a certain timeframe.

The Panel received a number of submissions and feedback in support of broadening the disease criteria beyond terminal conditions with prognosis of death within a relatively short (or any) time frame. Forum participants shared stories of watching loved ones suffer and have a traumatic and painful end-of-life process but they were not eligible for VAD as they did not have a terminal diagnosis.

“...the case for allowing the option of VAD for people who suffer unbearably from incurable disease but are not terminal, is based on the principles of autonomy, dignity and compassion”

- Marshall Perron, Submission 24.1

“..should include provision for those who are suffering long-term pain the cause of which cannot be cured in a manner the person considers tolerable should also be given the right to access VAD”

- Margaret Warburton, Submission 67

In light of this, the Panel gave close consideration to the requirement for a prognosis of death within a particular timeframe for access to VAD. As well as understanding why other jurisdictions have elected a particular timeframe, the Panel considered the issue of the particular challenges and barriers to accessing timely health services and support in the NT, particularly for those who live in remote areas. During the consultations, community members raised concerns about the possible inability to access necessary approvals if timeframes were too restrictive and the barriers too great.

The Panel observed that during the consultation phase of VAD legislation in other Australian States and Territories, the predicted life expectancy with the disease or medical condition tended to be 12 months but that in the course of debate on legislation, this time frame was reduced for the majority of conditions. Of the more recent jurisdictions to introduce VAD legislation, Queensland adopted a single, 12 month prognosis time frame. The ACT legislation does not include a specific time frame of prognosis for death due to the terminal condition.

The Panel concluded that a recommendation that no timeframe of prognosis to death would amount to a significant departure from the established VAD legislative frameworks that apply throughout Australia other than the ACT. The Panel had particular regard to the significant challenges faced in the NT in implementing VAD as have already been identified in preferring not to depart substantively from established practices. While the Panel noted with interest the different approach taken in the ACT, the Panel considered that there was insufficient evidence to support taking such an approach in the NT.

The Panel considered that the Queensland approach of a single prognostic time frame of 12 months applicable to all eligible medical conditions represents an appropriate, evidence based criteria. In the Panel's view, a time frame of 12 months would minimise or eliminate any prospect that an eligible person could not access the relevant health care services within the time frame so as to make VAD practically inaccessible.

The Panel acknowledges the views expressed by a number of respondents that VAD should be extended to allow access for people without any terminal illness or medical condition at all, and who have led a full, but 'completed' life. Whilst respecting those views, the Panel considered that the extension of VAD beyond the existing well established parameters of assisted dying for people facing intolerable suffering from a progressive and incurable condition which will cause death within a determined time frame, was outside the scope of this inquiry.

RECOMMENDATION 10

To access VAD in the NT, a person should have a serious and incurable condition which is causing intolerable and enduring suffering that cannot be relieved in a manner they feel is acceptable.

VAD eligibility shall be based on a prognosis of 12 months at the time of being assessed, irrespective of diagnosis and if the patient meets all other requirements.



4.4. Decision Making Capacity

In every Australian State, a person must have decision-making capacity at every stage of the VAD request process. This effectively rules out the possibility of a person nominating VAD in an advance personal plan or advance health care directive. Notwithstanding that state of affairs, the Panel received many requests that future VAD legislation allow for VAD to be carried out in accordance with a person's wishes after they have lost decision making capacity, particularly in the case of dementia. The issues regarding VAD and dementia are addressed later in this section and in Appendix 9.

The Panel recommends alignment with other jurisdictions regarding decision making capacity. The individual must have decision making capacity, as determined by the medical practitioner, at the time of making the decision to end their life.

Decision making capacity at all stages of the assessment process including the formal request to access VAD and the decision to administer a VAD substance are important safeguards not just for people who may access VAD but for all relevant health care providers involved in the provision of VAD services.

A person may have reduced decision making capacity in some areas such as financial management but may still have capacity to understand and make decisions on other areas of their day to day life such as end-of-life choices. It cannot be assumed even though a person has a particular type of illness or disability, that they do not have capacity to make any decisions.

The Panel received submissions from the NT Public Guardian and Public Trustee suggesting that specific criteria be developed for assessing the decision making capacity of people under guardianship or with an intellectual disability.

The Panel broadly supports the development of specific assessment criteria in the case of people with impaired decision making capacity. These criteria could be contained in clinical guidelines developed under the legislation with appropriate input from the disability and guardianship sector.

4.5. Mental Illness

In all other Australian jurisdictions, patients with mental health as a sole diagnosis are ineligible for VAD.

When the question was posed about whether to allow people with a primary diagnosis of mental illness access to end their life, the strong view was to align with other jurisdictions to exclude mental illness on the basis that it is not regarded clinically as a terminal condition.

The Panel recognised that people confronted with a terminal illness, or intolerable suffering may develop a mental illness as a consequence or reaction to their condition. The Panel considered the existence of mental illness secondary to a terminal illness or disease should not exclude a person from accessing VAD, provided that the mental illness does not result in a loss of decision making capacity.

4.6. Dementia and VAD

One of the most talked about aspects of VAD in the Panel's community consultations was whether VAD should be available for people with dementia. Broadly speaking, the progression of the condition in most cases of dementia is such that at the time of diagnosis, the prognosis of a timeframe to death is usually indeterminate or at the least, significantly longer than 12 months.

There are two identifiable pathways to making VAD available to persons diagnosed with dementia, each of which has its own range of issues or challenges. Firstly, consideration may be given to enabling a person diagnosed with dementia to be able to access VAD at a time prior to the dementia taking away the person's decision-making capacity. Secondly is opting to use an advanced directive.



No other jurisdiction in Australia has made it possible for a person to make an advanced directive which would enable assisted dying to be carried out after a person has lost decision making capacity due to dementia. It remains to be seen whether the different approach under ACT law, which does not require a prognosis of time frame to death, will lead to people diagnosed with dementia seeking to access VAD before they lose decision making capacity.

In light of the significant interest in the availability of VAD for persons suffering dementia, particularly through the provision of advanced directives, the Panel has undertaken more a detailed analysis of the underlying issues regarding extending eligibility for VAD to people suffering dementia, at Appendix 10.

In the case of dementia, the Panel acknowledges the strong desire of Territorians to be able to access VAD in the event of a diagnosis of dementia. The Panel observes that similar expressions of desire were made in each of the other Australian States and Territories at the time of consultation and implementation of their VAD laws. The Panel considers that the application of VAD to people with dementia by way of either a relaxation of eligibility criteria for prognosis of life expectancy, or by way of an advanced directive, should occur in a consistent manner throughout Australia as part of a national dialogue.

RECOMMENDATION 11

To access VAD in the NT, a person must have decision-making capacity at all stages.

VAD should not be available for persons solely diagnosed with a mental illness.



05

VAD PROCESSES

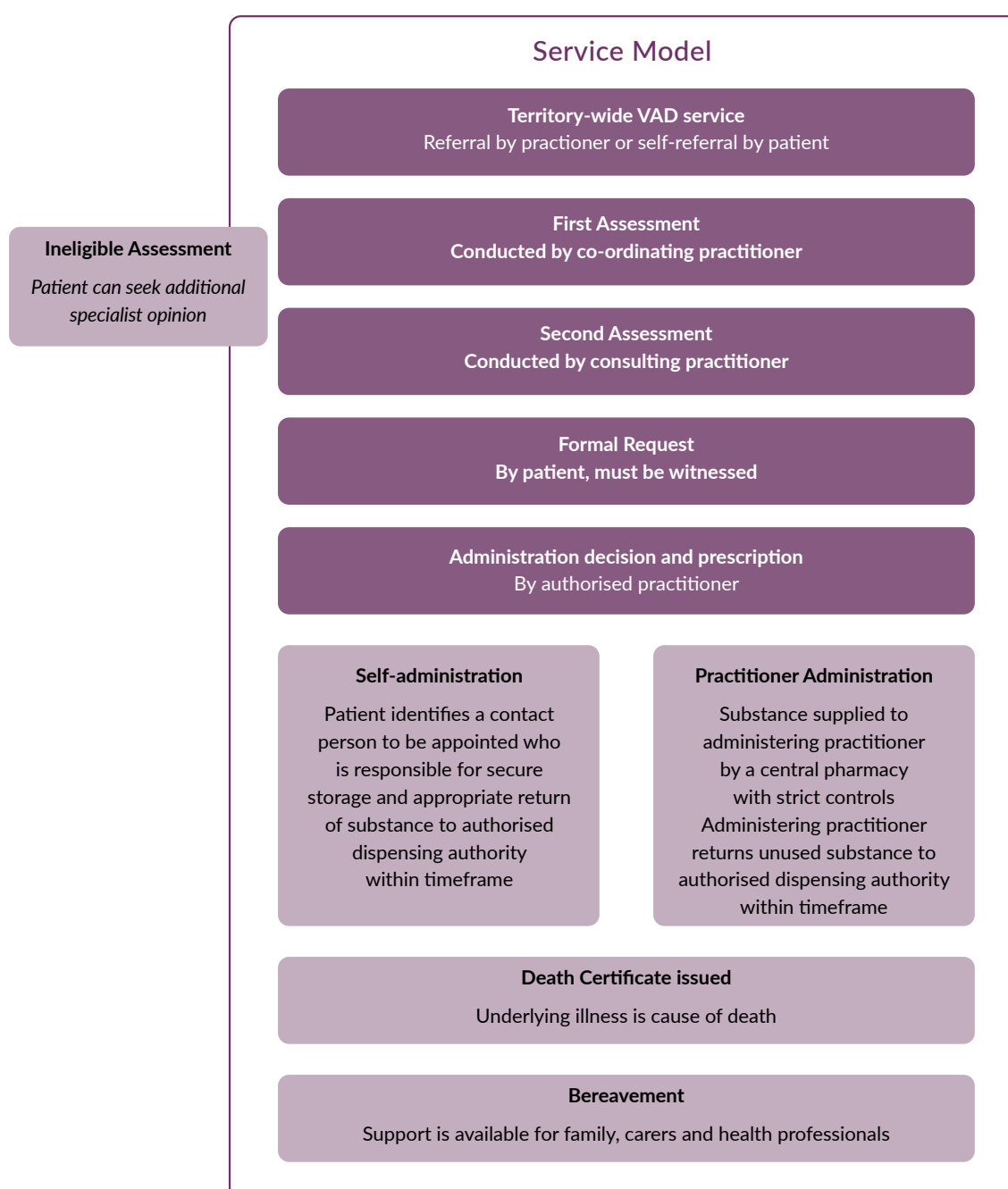


5. VAD Processes

VAD legislation in each Australian jurisdiction sets out the process which must be followed in order to obtain access to a VAD substance and complete VAD. Again, most jurisdictions contain broadly similar criteria for the VAD assessment and access process though there are some key differences between jurisdictions. The Panel's recommendations regarding the VAD process are based on a detailed consideration of submissions received and the large body of academic writing providing analysis of the effectiveness of various aspects of those VAD processes.

The Panel's consideration of processes in other places and their practical application to the NT have informed the Panel's recommendation of a centralised VAD service in the NT, which is materially different to other jurisdictions. The discussion and recommendations below are based upon consideration and support for the Panel's proposed centralised VAD service model.

The following diagram summarises the Panel's proposed process for VAD.



5.1 Initial request and initiation

The first step in the process involves making a request to be assessed for VAD to a medical practitioner.

In other jurisdictions, the initial request may be informal. It need not be in writing and it need not be witnessed. The request must be recorded on the patient's clinical record by the medical practitioner. In other jurisdictions if the medical practitioner is an eligible VAD practitioner then they would proceed to conduct the initial assessment. If they have a conscientious objection they may refuse. In some but not all jurisdictions that medical practitioner would be required to refer the patient to a VAD navigator service or practitioner willing to undertake an assessment.

An advantage of a centralised service model for the NT would be that the initial request by the patient would be referred immediately to the centralised service, effectively resolving most issues of conscientious objection or ineligibility of the patient's treating practitioner and immediately placing them within reach of appropriate supports. A person could make a direct request to be assessed for VAD to the centralised VAD service without having to go through their treating medical practitioner.

As each State has developed VAD legislation, a significant point of debate and decision-making has been the limitations, if any, on health care providers initiating the conversation about VAD with their patients. Victoria implemented an approach whereby doctors and other health care professionals were prohibited from mentioning VAD unless the patient broached the subject first. Similar provisions exist in South Australia. However in WA, Queensland and Tasmania, laws permit health care professionals to introduce the topic of VAD, as long as they also present all other options, including continued treatment and palliative care.

The following views were expressed around this topic:

"The doctor should be able to initiate the discussion." - Elisabeth Clark (Katherine Mayor)

"The so-called 'gag clause', which prevents doctors from raising VAD with their patients, was raised as a troubling barrier to people's right to know the full range of care and treatment options available if they are diagnosed with a terminal illness"

- Conference Report, VADCON 2023, hosted by Go Gentle Australia and VADANZ

"We do not support a gag clause, however patients should be informed of their options for palliative care at the same time that VAD is discussed with them."

- Heads of Departments, Alice Springs Hospital, Submission 80

"If clinicians are unable to raise the topic of VAD I fear people will not know their rights to access, and this is further discriminator towards people already with already restricted access to health care."

- Survey response

"The prohibition on raising VAD with patients contained in the Victorian VAD law. Some medical practitioners have reported feeling 'deceitful' or 'intellectually dishonest' adhering to this provision, and are concerned that it may be preventing patients from making an informed choice about their treatment options, particularly those from non-English speaking backgrounds or individuals with poor health literacy."

- Australian Centre for Health Law Research, Submission 41

In light of the experience interstate, the Panel supports the ability of practitioners to initiate discussions with patients about VAD. The Panel considers that VAD legislation should not contain a prohibition on practitioners initiating VAD discussions, provided that the practitioner informs the patient of all treatment options including the availability and scope of palliative care services.

RECOMMENDATION 12

Medical practitioners should be allowed to introduce the subject of VAD services to patients during discussion about treatment options.



5.2. Use of Telehealth

The *Commonwealth Criminal Code Act 1995* criminalises the use of telecommunications to disseminate “suicide-related materials.” Those provisions were interpreted in *Carr*³² to include using a carriage service (telephone, mobile phone, email, or the internet) to provide advice to patients about VAD.

Most VAD legislation provides for the limited use of telehealth in the assessment and consultation process. Various aspects of the process are undertaken electronically via a carriage service. This may include, for example, the use of e-prescriptions. However the effect of the decision in *Carr* is that the use of any of those carriage services for any aspect of a VAD service will constitute a criminal offence.

Nevertheless, subject to future amendment of the *Commonwealth Criminal Code*, the Panel considered the availability and suitability of telehealth and is able to report its findings and recommendations regarding the use of telehealth generally.

While face-to-face consultations are generally preferred for VAD, telehealth is now accepted as a valid method of health service delivery for many medical conditions. There are a number of issues/concerns affected by the ban on using telehealth services for VAD:

- It limits access for patients in remote areas where VAD services are unavailable.
- It excludes those unable to travel due to progressive, terminal and advanced medical conditions, specifically those potentially eligible for VAD.
- It effectively prohibits the use of phone or internet interpreters for those who need those services for VAD consultations.
- It is problematic in situations where in-person consultations may be unsafe due to infectious diseases like COVID-19.
- Health staff are concerned about the risk of breaching the *Commonwealth Criminal Code Act*.

The Panel also heard about the limitations of telehealth including:

- Telehealth makes it difficult for clinicians to identify other people in the room with the patient, which could increase the risk of coercion; and
- There is a clinical preference for face-to-face consultations, as they allow clinicians to better build a therapeutic relationship, demonstrate empathy, address complex issues associated with VAD, and interpret non-verbal cues.

Feedback from Territorians through meetings, submissions and the survey revealed most believe that at least some consultations should be conducted face-to-face due to the clinical factors mentioned above. However, they also agreed that certain information could be provided and other processes could be conducted via telehealth.

“Also, the system needs to be designed to not make it hard for people in remote communities - perhaps telehealth appointments with doctors are OK if there is a nurse with the patient face-to-face.”

– Survey response

“I think that the difficulties facing rural and remote living people will be enormous so telehealth must be considered.”

– Survey response

“For regional and remote locations we have to find the right balance for how much of it is going to be online and in person”

³² *Carr v Attorney-General (Commonwealth)* 2023 FCA 1500

– Tennant Creek community consultation

“Doing it over telehealth you’ll miss most of the cues. Had a meeting in Groote today regarding court and talking about culturally unsafe practices and the blame that could be put onto the person that’s sitting with the judge – took hours to just talk through this. Risks are so significant with telehealth – the follow up could be online if the first appointment is in person.” – Nhulunbuy community consultation

“Telehealth should not be used in the context of VAD.”

– Heads of Departments, Alice Springs Hospital, consultation

Regarding the peer-reviewed literature, health professionals expressed that telehealth is a “second rate solution”³³.

From the perspective of family caregivers, a study conducted by White et al demonstrated that not being able to use telehealth was an:

“absolute pain”, causing delays and suffering, leaving 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. They did, however, acknowledge the limits of telehealth care and that its use in VAD should be cautious. Some thought it appropriate after a first in-person consultation, while others noted challenges for conducting some neurological assessments and for people with communication difficulties³⁴”

The Panel concluded that there should not be an absolute prohibition on the use of telehealth for assessments or other steps in the VAD process. However, at least one assessment should be undertaken in a face-to-face consultation between the person requesting VAD and the co-ordinating or consulting practitioner.

The inability to use telehealth for providing VAD services has a financial and time cost. In cases where telehealth cannot be used, patients must either travel to see doctors or doctors must travel to see patients. In the NT context, travel is often long and logistically challenging. In addition, frail patients will often require an escort and accommodation, raising the question of who is responsible for the cost. The Panel heard that requiring patients to pay out of pocket will result in highly inequitable service delivery in the NT.

“Travel from and to Tennant Creek can be challenging and costly if people want to access VAD”

– Tennant Creek community consultation

“Will it be covered under patient travel?”

– Palmerston community consultation

In the absence of telehealth, other jurisdictions have implemented strategies to support outreach services. For example, in Western Australia, the Regional Access Support Scheme³⁵ has been implemented to fund practitioner or patient travel for necessary in-person consultations, aiming to ensure that regional residents are not unfairly disadvantaged by their geographical location in addition to the barrier imposed by the Criminal Code.

RECOMMENDATION 13

Subject to amendment of Commonwealth legislation, telehealth should be permitted for VAD purposes provided at least one assessment is conducted in person.

33 Participating doctors’ perspectives on the regulation of VAD in Victoria: a qualitative study Lindy Willmott , Ben P White, Marcus Sellars, Patsy M Yates

34 Ben P White , Ruthie Jeanneret, Eliana Close , Lindy Willmot, *Access to VAD in Victoria: a qualitative study of family caregivers’ perceptions of barriers and facilitators*, Medical Journal of Australia, 12 June 2023

35 <https://www.health.wa.gov.au/~media/Corp/Documents/Health-for/Voluntary-assisted-dying/Access-Standard.pdf>

5.3. Assessment

5.3.1. Assessment by two medical practitioners

Assessment of eligibility for VAD must be completed by two appropriately trained, qualified and experienced medical practitioners. This is the current approach in all other jurisdictions, apart from the ACT which has proposed the inclusion of nurse practitioners for one of the two assessments. Detailed consideration of the appropriate level of medical training and qualification by assessing practitioners is discussed in Chapter 2 of this report under “VAD Practitioners”.

In other States the first and second assessments are organised around different roles. The first assessment is performed by a doctor known as the Coordinating Practitioner and the second assessment, is also made by a doctor referred to as the Consulting Practitioner³⁶. The Coordinating Practitioner leads the care of the patient, and is required to locate a doctor who is able to provide a consulting assessment. Slightly different terminology is used in different States.

In their written submission to the Panel, Professors Wilmott and White of the Australian Centre for Health Law Research shared their model legislation for VAD³⁷ which provides for two independent medical assessments as the recommended process. They also suggested the NT consider including nurse practitioners in this role³⁸ as considered in the ACT. Some attending the NT public consultations also suggested other classes of health practitioners, such as registered nurses or paramedics, might be able to perform these assessments.

The Panel's proposed centralised model for providing VAD would allow the NT to develop a team-based approach to care, notwithstanding the requirement for the two medical assessments to be completed independently. This would allow for the Coordinating and Consulting Practitioners to be readily identifiable and accessible, preventing delays due to lack of available qualified medical practitioners able to undertake one or the other of the two required assessments.

5.3.2. First assessment

The Panel heard that the majority of respondents considered that the first assessment of eligibility for VAD should be undertaken by a medical practitioner.

There were a number of dissenting perspectives provided by some community members who felt that VAD is a right from which they should not be obstructed by anyone, including medical practitioners. For instance:

“While there should be some checks and balances eg an existing APP, a cooling off period, an obligation to seek medical advice on options with discussion on prognosis, side effects etc, it should be the decision of the person or their approved decision makers. A human right in my view. I should not need to seek a doctor's authority, however prescribed, to end my life.” - Brian Radunz, Submission 6

Despite the view that it is a human right which should not be constrained by medical processes, no Australian jurisdiction has adopted this approach. All have legislated for VAD on the basis that it is being made available to people who are already dying of a terminal condition, and all therefore require medical involvement to confirm the eligibility for VAD, based on diagnosis and prognosis.

Some Australian jurisdictions require the assessing medical practitioner to consult with a medical practitioner with specialist expertise in the medical condition which is likely to cause the patient's death. The Panel considered that on balance, such a requirement was better left to clinical judgement rather than legislation. A requirement to seek specialist confirmation in every case could provide a significant barrier to access to VAD

³⁶ Victorian legislation

³⁷ White and Wilmott *A Model VAD Bill* (2019) 7(2) Griffith Journal of Law and Human Dignity.

³⁸ White and Wilmott, written submission.

when it may not be required in many cases. Where the assessing practitioner is operating within a centralised VAD service model greater opportunities for professional collaboration and advice will arise.

5.3.3. Second assessment

In other States the second review is also by a medical practitioner who is referred to as a Consulting Practitioner. The Consulting Practitioner is required to repeat the same steps as the first assessing practitioner, including providing the same specified information to the person about diagnosis, treatment options, life expectancy and so on. With a few minor exceptions, the second process mirrors, or duplicates the first.

The need for a second assessment requires balancing between the rights of an eligible person, including autonomy of decision making and choice, and necessary safeguards within the assessment process to ensure public confidence in the VAD system. It also provides reassurance the system is rigorous and contains adequate protections.

The Panel concluded that the second consulting assessment should be retained as part of the assessment process. If the centralised model of VAD service is adopted, the VAD service would be able to ensure ready access to Consulting Practitioners to ensure the assessment processes can occur without delay and unnecessary distress to the patient or their family.

RECOMMENDATION 14

The VAD assessment process shall involve two stages of assessment conducted by appropriately qualified medical practitioners.



5.3.4. Components of the assessment

At both assessments the assessing doctors are required to consider whether the person meets all of the eligibility requirements for VAD, whether they have the decision-making capacity to make a decision about VAD, and whether there is any coercion, undue pressure or abuse affecting their decision. These are matters for clinical judgement, but they underscore the importance of an assessing practitioner having the relevant qualification and experience to be able to undertake such an assessment. Legislation does not prescribe how assessors should undertake assessments. These are matters which the Panel considers are better left for the development of clinical guidelines as has occurred in other jurisdictions.

Legislation in other jurisdictions lists the information which must be provided to a person once assessed as meeting the eligibility criteria for VAD. This typically includes the following:

- a. the patient's diagnosis and prognosis;
- b. the treatment options available to the patient that would be considered standard care for the disease, illness or medical condition with which the patient has been diagnosed and the likely outcomes of treatment;
- c. the palliative care and treatment options available to the patient and the likely outcomes of the care and treatment;
- d. the potential risks of self-administering or being administered a VAD substance likely to be prescribed under this Act for the purposes of causing the patient's death;
- e. that the expected outcome of self-administering or being administered a substance referred to in paragraph (d) is death;
- f. the method by which a substance referred to in paragraph (d) is likely to be self-administered or practitioner administered;
- g. the request and assessment process, including the requirement for a written declaration signed by the patient, or a person on the patient's behalf, in the presence of two witnesses;
- h. that if the patient makes a self-administration decision, the patient must appoint a contact person;
- i. that the patient may decide at any time not to continue the request and assessment process or not to access voluntary assisted dying;
- j. it is unlawful for a person to apply pressure or duress on the patient to request VAD or to continue the request and assessment process;
- k. that if the patient is receiving ongoing health services from a medical practitioner (the treating practitioner) other than the coordinating practitioner, the treating practitioner may not withdraw from treatment because the patient has requested VAD; and
- l. that if the patient is a resident of a residential facility, whether permanently or not, the patient should inform the residential facility manager about the patient's request for access to voluntary assisted dying.



5.4. Formal request

Following the assessment process a person must make a formal request for VAD. In other jurisdictions there is a requirement that this request be in writing and witnessed by an eligible witness. Where an interpreter is necessary, the interpreter must also sign the request and certify the request is a voluntary request made by a person with capacity, and the person understands the request they are making.

The Panel received a number of comments and submissions stating that the requirement for a written request and a signature could pose a barrier to people with poor literacy or from different cultural backgrounds, particularly Aboriginal Territorians.

In other States, the legislation contains provision for another person to sign the request if the requestor is incapable of signing it themselves. This may be contrasted with the initial request and the later, final request at time of administration, which requires a verbal request or other unambiguous gesture from the person themselves.

The Panel supports the requirement for one formal request to be recorded in writing confirming the person has requested VAD. It is appropriate that this formal instrument be created after the person has been assessed as eligible. It is also appropriate that the request be witnessed by a person.

Although it will be necessary to build in flexibility for people who cannot sign for any reason (whether due to their illness or not), this has been achieved in other legislation. The formality of a signature (with due allowance) enables an important safeguard to be met namely, confirmation that the request is voluntary, enduring and comes from the person themselves.

In addition, all VAD legislation requires that a formal request cannot be made until the end of a determined timeframe after the first request. This requirement is intended to ensure that the coordinating practitioner is satisfied that the person's request is enduring and not coerced. In cases where the person may die or lose capacity if required to await the determined timeframe, the coordinating practitioner and consulting practitioner can authorise an earlier request.

RECOMMENDATION 15

Following the assessment phase, the person must make a formal request for VAD in writing which is independently witnessed. Provision should be made where a person is physically unable to provide a formal written request.

The timeframe before a formal request may be made should be broadly consistent with timeframes in VAD legislation in other Australian jurisdictions.



5.4.1. VAD Administration Permit

Following a formal request for VAD by a person, the process of approval and administration becomes more variable between other jurisdictions.

In some States there is a requirement to seek a formal permit either from the Review Board or Commission, or from the department CEO. Once the permit has been issued the or authorisation Coordinating Practitioner may then issue a prescription for the VAD substance which is then provided to the person, or retained by the practitioner who will administer the VAD substance. Other jurisdictions leave the management of the process in the hands of the Coordinating Practitioner, subject always to strict reporting requirements to the Board.

The Panel considers it is preferable for the critical decision making processes to occur within the clinical relationship between the person and their Coordinating Practitioner, with the Review Board providing oversight of compliance by way of post-event review rather than as gatekeeper. This reduces the number of external decision makers required to complete the process and reduces the burden on the person seeking VAD. It essentially respects the autonomy and choice of the person seeking VAD by enabling the process to occur in a more or less normal clinical setting.

Where the Panel's preferred model of a centralised VAD service is involved, there would be even more reassurance that the procedures will be properly adhered to and rigorously supervised, given the continuity of the involvement of all practitioners participating.

The Panel supports a process whereby the Coordinating Practitioner has a time limited obligation to report to the Board that a person has been assessed as eligible for VAD and has made a formal request which the Coordinating Practitioner intends to act upon. This would negate the need for a permit.

The Panel supports the requirement that the Coordinating Practitioner notify the Board of the issuing of a VAD substance prescription along with other notification requirements. The Panel supports the inclusion of a requirement that the prescription must make it clear that it is for the purposes of supplying a VAD substance for administration under the Act.

RECOMMENDATION 16

The VAD process should not require the issuing of a permit but rather allow the Coordinating Practitioner to approve the request and issue a prescription, subject to strict reporting requirements.

5.4.2. Administration Decision

In some States, person must make an administration decision. This is a decision whether to self-administer the VAD substance or seek practitioner assisted administration. The choice of self-administration or practitioner assisted administration triggers different pathways of decision making and approval centred on supply and storage of the VAD substance.

In most jurisdictions the default position is that a person must self-administer the VAD substance unless they are unable to do so for specified reasons. Practitioner assisted administration is only available where self-administration is impractical. More recent legislation has permitted greater choice by the eligible person for example, in New South Wales. Where a choice has been permitted, early indications are that eligible persons prefer practitioner assisted administration to self-administration.

Where a person is either required to, or chooses to self-administer, they must nominate a Contact Person. The Contact Person has a range of responsibilities, discussed below. The Contact Person is required to sign a declaration to the effect that they understand those responsibilities and consent to providing information to the Review Board if required.



5.5. Witnesses

Family members, particularly spouses, have a very important part to play in the decision making process for VAD. While the legislation requires the decision must be made by the person individually, and in the absence of any sign of coercion, nevertheless the broad experience of those involved in the passing of a loved one through VAD is that there was a consensus amongst family members to respect the wishes of the dying person and to enable it.

In consultations with Aboriginal Territorians, significant emphasis was placed on the importance of whole-of-family decision making around important health and treatment decisions, including withdrawal of treatment and entering into palliative care, particularly around returning to community to pass away. The role of family, including important responsibilities and rights, was said to be of vital cultural importance, including for ensuring the safe passage of the person into the afterlife. In that context, complex rules regarding which family members have specific responsibilities and decision making authority need to be properly understood and respected.

Against that background, the Panel considered the question of witnesses.

Legislation in other States contain requirements, with some variations, that an eligible witness must not knowingly be a beneficiary to any estate of the person requesting VAD. This is an important safeguard against coercion or abuse but at the same time, would effectively exclude the most important people from the formalities of the decision making process.

The legislation is expressly concerned with family members who might receive a financial benefit but fails to recognise or acknowledge that in other cultural contexts a person may stand to gain important cultural, decision making, or other powerful rights and authority as a result of a person passing away.

The Panel considered a requirement that excludes family members or culturally significant decision makers from being a witness is too restrictive. The Panel considered a balance could be achieved by providing a requirement that the formal request be witnessed by at least one independent witness and may also include other witnesses.

This would permit a spouse or family member to be a witness even if they were a beneficiary of the person's estate or otherwise a culturally important 'beneficiary' after the person's death.



5.6. Self vs Practitioner Administration

Some jurisdictions only permit practitioner or clinician-assisted administration if the person is physically or for other practical reasons incapable of self-administering.

Western Australia was the first jurisdiction to permit a person to choose between self-administration and practitioner assisted administration. Early findings from Western Australia suggest that there is a clear preference for people to have clinician-assisted VAD.

The Panel supported the right for a person to choose between self-administration and practitioner administration. That discussion should be part of the first assessment, and once a person's request is approved, the VAD service will then be able to start more detailed planning with the person.

One of the critical issues for self-administration is the supply, safe storage and disposal of the VAD substance. In the NT this could pose substantial challenges, particularly in relation to the transportation and storage of a VAD substance in remote areas. The Panel recognised that individual circumstances of a person may make the option of self-administration too risky. However, assessment of a person's suitability for self-administration would optimally occur as part of the assessment and request process with the Coordinating Practitioner. Under the Panel's recommended centralised VAD service model, the Navigator Service would assist with assessing patient safety, substance control issues and the like and encourage a person to take the safest course possible. Relevant assessment criteria for whether a person should be approved for self-administration rather than practitioner administration are appropriately developed by the VAD service under the oversight of the Review Board.

Sometimes it may transpire that a person may initially choose self-administration but later decide, or circumstances dictate, that VAD should occur by way of practitioner administration. Such a change may be sometimes required because of changes in the person's physical ability to manage the self-administration process, or due to other changes in their circumstances or wishes. The Panel considers that the capability for such changes should be built into VAD legislation, with the proviso that the Review Board should be notified of any change and the reason for it, and the VAD substance (if already provided) should be returned to the Pharmacy service and reissued to the administering practitioner.

5.6.1. Contact Person

In other States, where self-administration is the default or the person chooses self-administration, the person must nominate a Contact Person. This may be anyone over the age of 18. The Contact Person has responsibilities connected with the storage of the substance, disposal of the substance and reporting of the death of the person (whether or not as a result of administration of a VAD substance).

The Contact Person is lawfully entitled to be supplied, to possess and to supply to the person, the VAD substance. The Contact Person is entitled to possess any unused portion of the VAD substance and supply it to an authorised disposer for the purposes of its disposal.

The Contact Person is required to complete a form in which they certify that they understand and accept their obligations and that the Review Board may ask them for information in relation to the subject VAD case. Provision is also made for interpreters where required.

The Contact Person is responsible for notifying the co-ordinating practitioner of the death of the person and whether or not the death was a result of administration of a VAD substance. The Contact Person may handle and help prepare the substance however the VAD recipient must actually take the medication themselves.

The Panel supports the inclusion of a requirement for a Contact Person in similar terms to that which operates in other States, where the person has chosen self-administration of the VAD substance.

In some jurisdictions, authorisation to possess and supply the VAD substance to the person for self-



administration is extended to an 'agent' of the person. Where reference is made to an agent of a person, it is undefined by the legislation.

This could lead to legal uncertainties regarding the status of persons other than the nominated Contact Person and could result in the VAD substance being under the control of those who have not been required by law to certify their understanding of their obligations under the Act.

The Panel considers it would be preferable to remove any reference to a person's agent and instead limit authority to the person and the Contact Person or otherwise, to impose the certification requirement so as to capture anyone who takes any part in the process of preparing for the self-administration of the substance.

5.7. Substance

During the consultation process, the Panel sought views from the public, key stakeholders and experts ensure a balance between appropriate safeguards that protect people from misusing a Substance and excessive barriers that prevent people from accessing and using a Substance when they are ready and eligible.

The prevailing view from the consultation process when the matter of substance safety was raised supported processes that ensured substances were strictly controlled to protect the community from harm. In other Australian States, there are legislative provisions in place to ensure substances are supplied, stored and disposed appropriately. It is the view of the Panel that similar provisions apply to any relevant VAD legislation in the NT.

Supply of Substance

In general, legislation in other jurisdictions provides for the supply of the Substance to the person or the contact person to allow self-administration to occur at the time of the person's choosing. Supply is facilitated by a pharmacist, with specific requirements applicable to supply. Typically, the pharmacist is required to verify all aspects of the prescription including as to the prescribing clinician's eligibility as a Coordinating Practitioner under VAD legislation and must independently inform the person and or contact person of the same matters as the system practitioner.

Under the Panel's preferred model of a centralised VAD service, the Pharmacist will be able to readily verify the validity of the request and be satisfied that all preceding criteria have been met before providing information to the person and dispensing substance. In addition, the centralised model would reduce the prospect of delay due to the inability to locate the Pharmacist who is qualified to dispense Substances and/or who does not have a conscientious objection.

Storage of Substance

Self-Administering

The eligible person accessing VAD will be responsible for maintaining the supplied Substance in a safe and secure way. The appointed Contact Person is to be notified of the secure storage location of the supplied substance.

All jurisdictions except Western Australia legislated that the Substance must be stored in a locked box. In the WA legislation there is simply a requirement to inform the recipient how to store the Substance in a safe and secure manner. A decision to use safe boxes or similar may be a policy decision rather than requiring legislation.

During the Panel's community consultation, there were concerns raised regarding the potential use of Substances in locations outside of a domestic residence, such as residential aged care facilities or public hospitals. It is acknowledged storing Substances in such environments may require consideration of relevant policies and procedures (scheduled medicine storage legislative provisions may apply). Despite this, a person is



not legally compelled to disclose the possession of Substances. Understanding a persons' intent to use their VAD substance may mitigate potential issues in these settings (misplacement or diversion) with appropriate guidance and support from the Coordinating Practitioner or the Navigator Service.

During consultations, there were additional concerns raised in relation to the safe dispensation and storage of VAD Substances in the community. The consultations reiterated a need to identify solutions that were appropriate to the NT context.

"We recommend that the Expert Advisory Panel examine systems now operating under state VAD laws for the dispensing, transport, storage, and return of a VAD substance in the interest of determining the most secure system suitable for the NT's needs while ensuring conditions for its operation maintain public safety but are not overly onerous."

– Clem Jones Group, Submission 15

Additionally, Alice Springs based pharmacists raised the potential for misdirection and inadvertent access of substance, if substance were delivered to remote communities in the usual manner – packaged and sent via airmail to the local Health Centre, where packages may sit awaiting collection in airport trolleys. The Heads of Department Alice Springs Hospital submission (#80), identified the need to have 'senior pharmacist involvement...and that specifically Central Australian knowledge will be needed.'

The Australian Medical Association NT Branch (AMA NT) raised concerns about the potential for misuse of Substance in the community, and recommended appropriate safeguards to mitigate such occurrence.

"Significant care has to be taken with the dispensing and storage of VAD medication. Ideally, such VAD medication should be maintained in pharmacies and obtained by the individual at a time of their choosing, rather than be maintained in a domestic environment."

– AMA NT, Submission 11

After a person has died, whether from administration of a Substance or not, responsibility for return of the substance and reporting to the co-ordinating practitioner and Review Board passes to the Contact Person.

Practitioner Administering

Under legislation in other States, if the substance is issued to an administering practitioner, the administering practitioner must notify the Review Board that they have received the Substance. The administering practitioner must notify the Review Board of the death of the person irrespective of whether by use of the substance or not. The administering practitioner is required to either safely dispose of, or return the Substance to the pharmacist and notify the Review Board. The pharmacist is required to notify the Review Board of the return and disposal of the Substance.



RECOMMENDATION 17

The VAD legislation should provide for safe supply, storage and disposal of the substance, including a contact person for VAD.

The VAD legislation should provide for a contact person to be appointed by a person who elects self-administration for VAD

5.8. Death Notification and Certification

In other States, notification of a death following self-administration is the responsibility of the Contact Person. In addition, the Contact Person must notify the co-ordinating practitioner if the person dies from another cause, i.e. they did not self-administer the Substance.

This ensures a complete record of the VAD process is maintained even if the person did not ultimately use VAD. Reviews undertaken of VAD systems in other States have shown information about how many people actually went through with administering a Substance is useful and important information in the evaluation of the system.

Also, the system of assessment, approval and administration is subject to a process of certification throughout and is supervised by the Review Board. It is important to ensure that for every person who commences the process of a VAD request, the Review Board has complete visibility of the person's involvement in the process and understands whether the process was completed by administration of a Substance or was interrupted by the person's death from other causes. Full knowledge of the process from the beginning to its end is critical to ensure the appropriate supervision and scrutiny of all aspects of a person's access to VAD services to ensure standards are maintained.

In cases of practitioner administration, the administering practitioner must notify the Coordinating Practitioner (unless they are the same person). In all cases, the Coordinating Practitioner must notify the Review Board (or equivalent).

In most other jurisdictions, the Act specifies that for the purposes of a death certificate, the cause of death must not state that the person's death was a result of VAD. However the NSW requires (requires and Act are transposed) Act cause of death as a result of VAD to be specified.

Some jurisdictions require the medical practitioner who certifies death of the person to report to the Registrar of births, deaths and marriages, that the death was a result of taking a Substance.

The Panel considers that notification of death of any person who has requested VAD be made to the Review Board. The Panel considers that otherwise, normal reporting obligations in respect of a death of a person should apply to cases involving VAD.

The Panel considers that the Act should specify that a death certificate must not state that a person die as a result of VAD and instead, the cause of death must be nominated as the underlying eligible terminal illness disease or medical condition.



The Panel consulted the NT Coroner regarding both death notification and cause of death certification. The Coroner considered notification of every VAD death would not be required if an independent Review Board was responsible for review of all VAD cases.

The Panel considers that the Act should contain a requirement that the Review Board must notify the Coroner:

- a. immediately after it becomes aware of any case in which a person has died as a result of a Substance and which did not comply with the certification and notification requirements of the Act;
- b. immediately after it becomes aware of any case in which a person has died as a result of a VAD substance where it suspects that the person did not meet all of the eligibility requirements of the Act;
- c. immediately after it becomes aware of any case in which a person has died following complications arising from administration of a Substance; and
- d. annually or at such other regular interval as deemed appropriate as to the total number of VAD requests initiated, the proportion of those cases in which death occurred, and the proportion of those cases in which death occurred as a result of administration of a Substance.

RECOMMENDATION 18

The Contact Person and Coordinating Practitioner must notify the Review Board of all deaths of persons who have made a formal request for VAD.

Notification to the Coroner should not be specifically required.

The cause of death of a person who has died by VAD shall be the underlying disease or illness that would have led to the person's death without VAD.

06

OVERSIGHT AND REVIEW



6.1. Review Board

Consultation, submissions and survey findings

Many of the Panel's consultations with expert stakeholders and community members involved discussion around a Review Board that could serve as a safeguard to monitor, evaluate and conduct continuous improvement. Expert stakeholders and community members supported establishing an independent oversight body. The survey results indicated 74 per cent of Territorians strongly agreed with the establishment of an independent oversight body to review and ensure compliance. The consultations explored themes around staffing, selection of members, data collection and sharing, complaints management, membership, structure, functions and legal powers.

Further evidence from submissions emphasise and address the need for an independent oversight body to ensure continuous improvement of VAD.

"AMSANT notes the Committee's question about establishing a Panel of Practitioners to oversee VAD. Clinical oversight is obviously essential. However, VAD is not exclusively a medical issue and to limit governance arrangements to include clinicians alone ignores the deep cultural and social significance of the issues associated with the process of dying, death and grieving."

– AMSANT, Submission 91

"The ALA contends that ongoing oversight and review of the NT's VAD Scheme is crucial for ensuring ongoing safety and accessibility...The ALA refers the NT Government to all six state jurisdictions, which have established statutory bodies for these purposes."

– Australian Lawyers Alliance, Submission 50

For the purpose of this Report, the independent oversight for VAD is referred to as the Review Board.

Most Australian jurisdictions have established and legislated an independent statutory body in the nature of a Review Board. Consistent with other jurisdictions, the Panel recognises the need for establishing and legislating a Review Board for the NT. The Panel considered findings and evidence associated with similar Review Boards in other jurisdictions, including Western Australia, South Australia and Victoria. The Panel believes establishing a Review Board that is authorised and appropriately resourced will strengthen proper adherence to the legislation and improve safety and quality of service and systems.

Membership

The importance of membership has been raised in many consultations. The Panel considered that membership of the Review Board should reflect its independent oversight function but also contain the right balance of geographical and cultural diversity appropriate to the subject matter.

In Western Australia, the Review Board consists of five members inclusive of medical practitioners, a lawyer and a person who has worked in the human rights area (VAD Act 2019). Similarly in South Australia, Review Board members are appointed by the Minister and consisting of a psychiatrist, a palliative care nurse, doctors, lawyers, a pharmacist, an Aboriginal community representative and a general community representative (VAD Act 2021).

The Panel acknowledges the importance of having a Aboriginal person on the Review Board to provide guidance, in relation to matters sensitive to Aboriginal culture and traditions.

The Panel also considers that regional representation is important, particularly amongst the health practitioner appointments. It may be appropriate to mandate that at least one health practitioner member of the Panel must be practising in the Central Australia.



Function

The Panel found that most Review Boards have substantially similar functions. Legislation in other States provides for a range of functions for the Review Board. In addition, the Review Board is required to provide information to various other entities, including the Police Commissioner, AHPRA and the Coroner where relevant to the functions of those entities. The Panel considered the language of the Queensland legislation provides a clear and succinct description of a Review Board's functions and powers.

Typically, such functions include:

- monitor the operation of the Act;
- monitor compliance with VAD processes in all cases and report any issues of non-compliance to relevant authorities;
- review all VAD cases including cases that do not involve complete death by assisted dying under the Act;
- provide advice, information and reports to government including an annual report on the operation of the Act and recommendations for continuous improvement;
- oversee the setting of standards for experience and practice; training and qualification requirements for all persons involved in providing VAD services;
- oversee the provision of community education and resources;
- oversee the provision of education and resources for health professionals;
- facilitate the conduct of research, review, and analysis in relation to information provided to the Review Board by practitioners;
- collect, use and disclose data or information in relation to the Act for the purposes of performing its functions;
- facilitate the statutory review of the Act;
- any other functions given under the Act; and
- oversee development, implementation and any necessary adjustment of clinical guidelines relating to VAD processes.

The Review Board should be empowered to include an ability to request information from the CEO of Health and from any accredited person providing any aspect of a VAD service, which would include people providing such services as interpreting, bereavement support or chaplaincy. The Review Board should also have the power to require information to be provided to it by a contact person or a treating medical practitioner of an eligible person.

RECOMMENDATION 19

An independent statutory body (Review Board) should be established to monitor compliance in every case and to review the operation of the Act. The functions, membership and responsibilities of the Review Board should be as outlined in Chapter 6 of this Report.

Complaints management/compliance

The Panel recognises the need for a thorough and clear complaints processes. However the Panel considers that issues of professional conduct of health practitioners should come within the existing framework of discipline under the Health Practitioner National Law and specific NT health practitioner legislation.

6.2. Data Collection and Sharing

Data collection is crucial for various aspects of VAD. It helps to understand how VAD processes impact patients, carers and health professionals. It facilitates the identification of any challenges that may arise during the implementation of VAD across the Territory. In addition, it provides information to support the development, prioritisation and evaluation of VAD policies. It also provides a safeguard by monitoring compliance with associated regulations and reporting any issues to the Review Board. Finally, it can ensure prospective assessment of potential benefits and concerns about VAD in the future.

The Panel has considered the nature of data collected regarding VAD to ensure it adequately meets the reporting needs of the oversight body and enhances understanding of the practice.

VAD Review Boards nationwide gather some data, primarily focusing on basic clinical metrics and compliance, however, this data does not address broader experiences or social impacts. Additional data collection and assessment of the widespread effects of VAD rely on research groups, often receiving temporary funding, resulting in inconsistency and lack of coordination. In contrast, Canada has adopted a federal approach to data collection, encompassing elements beyond VAD alone, such as the person's access to palliative care. There is a clear necessity for a national, cohesive process for prospectively collecting data uniformly across Australia.

The Panel supports the establishment of a nationally co-ordinated process of ongoing data collection, such as a national reference centre, which would foster collaboration among practitioners and researchers nationwide. This national reference centre could collaborate with researchers and practitioners across all States and Territories.

6.3. Appeal Mechanism

Most VAD laws identify some decisions about eligibility which are capable of administrative review or appeal. In South Australia, Victoria, Queensland and Western Australia the State Administrative Tribunals are the central bodies that have the power to hear reviewable decisions under each Act. In Tasmania, the VAD Commission (Tasmania's equivalent of a Review Board) has the jurisdiction to review decisions relating to VAD. In New South Wales, reviewable decisions are heard by the Supreme Court.

The Panel acknowledges the need for any appeal mechanism to be of a timely and manageable nature to ensure the process does not cause any unnecessary distress.

In the NT, the NTCAT has jurisdiction in a range of subject areas which complement the type of issues that may arise under VAD legislation. These include decisions on mental health issues, health profession regulation and guardianship of adults. Some informal responses to the Panel have indicated concern about the capacity of the NTCAT to respond with the necessary speed in cases, particularly where a person is at risk of imminent loss of decision making capacity.

Alternative avenues of review considered by the Panel include the following:

- a. Review to the centralised Review Board established under the Act. Although this would provide for subject matter expertise, it may lead to a perception that the Review Board is reviewing critical clinician decisions it had supervised. Hence perceptions of a lack of independence may arise which could have the effect of undermining confidence in the integrity of the VAD service and whether it meets acceptable levels of accountability and scrutiny.
- b. Review to the Supreme Court. In an appropriate case, the Supreme Court can act rapidly to grant urgent relief, including injunctive relief to any person with a sufficient interest in a matter. The disadvantage of placing any legislated review functions with the Supreme Court is that by its nature, the Court tends to be more formal, less easy for non-legally represented persons to navigate, and potentially lead to a more legalistic interpretation of matters which are, at their heart, matters for judgment in an individual case.



In New South Wales, Tasmania and Western Australia, the Act specifies that nothing in the Act is intended to limit the inherent jurisdiction of the Supreme Court. A provision to that effect would preserve entirely the jurisdiction of the Supreme Court to hear a matter in appropriate circumstances. However, the Court would have regard to the Act and the availability of review mechanisms within the Act as a matter of discretion in deciding whether or not to hear a matter, either on an urgent basis or at all.

The Panel has considered VAD legislation in other Australian jurisdictions, and has taken guidance from this legislation when recommending which decisions should be reviewable under the proposed new legislation.

The Panel considers that only some decisions on eligibility criteria are appropriate for review. Other jurisdictions have observed that some of the relevant eligibility criteria are based on clinical assessments/judgements and have concluded that it would be inappropriate for a review body which does not have the requisite clinical knowledge or experience to be able to overturn such an assessment. It is recommended that the following decisions are open to review by NTCAT:

- Whether the person meets the residency requirements (including eligibility for exemption);
- Whether the person does, or does not, have decision making capacity; and
- Whether the person is, or is not, acting voluntarily and without coercion.

The Panel considers that decisions such as disease diagnosis or prognosis of life expectancy should not be reviewable decisions.

In other jurisdictions, those who are entitled to apply for review are:

- the person whom the decision directly relates (e.g. the person who is trying to access VAD);
- an agent/family member of the person whom the decision directly relates; or
- any person who the Tribunal (e.g. SACAT, VCAT) is satisfied has a special/sufficient interest in the care of the person attempting to access VAD.

The Panel considered that it would be inappropriate to create a statutory right for family members of a person who has requested VAD to challenge such a request. The Panel was concerned that this could lead to unwelcome legal proceedings being brought by family members or others to try to prevent a person from carrying out their wishes to access VAD.

The Panel considered that appeal or review rights should therefore be limited to the eligible person themselves.

RECOMMENDATION 20

There should be a right of review to the NTCAT for some VAD decisions on eligibility, limited to only the person seeking access to VAD.

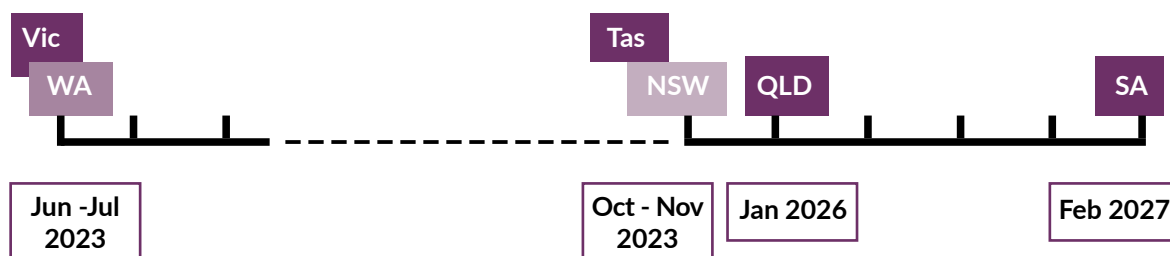
The VAD legislation should expressly preserve the inherent jurisdiction of the Supreme Court.



6.4. Review of the Act

All other Australian jurisdictions have included a requirement that the responsible Minister review the operation of VAD legislation within a timeframe of between three to five years after commencement.

VAD Act Review Timeline



The above timeline was part of VAD South Australia's submission (#14). It shows when each jurisdiction is to undertake the review of its Act.

Queensland included a review requirement of the Act based on stakeholder expectation that any legislation introduced to enable VAD was “*functioning as expected and continuing to meet the expectations of the community and medical practitioners.*”³⁹ Western Australia recommended a review of legislation (three years after the date of operation, every five years thereafter) to ensure that contemporary views and practices remain reflected in the legislation⁴⁰.

The Panel acknowledges that the relatively new and far-reaching social implications of VAD legislation justify including a formal obligation of operational review in the legislation itself. The first such review should be within the first few years of operation to ensure that the legislation operates as intended and does not cause harm to any sector of the community or the community as a whole.

The Australian Lawyers Alliance submission to the Panel (#50), stated they “[contend] that ongoing oversight and review of the NT’s VAD Scheme is crucial for ensuring ongoing safety and accessibility.”

VAD South Australia, in their submission to the Panel (#14), stated (under sub-heading ‘State reviews of VAD Acts’) that “*the NT has the opportunity to learn from the Australian states and those jurisdictions overseas where a VAD equivalent is a legal choice. The NT has the opportunity to develop an Australian model which reflects community expectations of a non-discriminatory compassionate choice at the end-of-life.*”

RECOMMENDATION 21

The first review of the operation of the NT VAD legislation should be delivered as soon as practicable after the third anniversary of its commencement. After that, reviews should be conducted at five year intervals.

³⁹ Report No. 34, 56th Parliament - Voluntary assisted dying, para 9.11, pp. 146.

⁴⁰ WA Ministerial Expert Panel on Voluntary Assisted Dying, Final Report, recommendation 31 (policy intent).

07

IMPLEMENTATION



7.1. Timeframe for legislation

Each jurisdiction has passed legislation with a defined period within which it must become operational. Most jurisdictions provided for a period of 18 months. This time period enables the necessary structures to be put in place to allow for setting standards, training, accreditation and the like. Where a defined period was not included, the experience was that implementation took longer.

The Panel has considered the unique challenges of establishing a VAD system in the NT and the work which will be necessary to meet the recommended centralised system approach.

Given the NT is the last Australian jurisdiction yet to implement VAD legislation, it may be assumed that assistance with development of systems, education and accreditation could occur more quickly than other jurisdictions. Many responses to the consultation included comments to the effect that the return of VAD legislation to the Territory is long overdue and should be implemented as soon as possible and without further delay.

“The sooner it’s introduced, the better”

– Survey response

“Yes. My father wanted Assistant (sic) dying when he was ill. The doctors told him that there was nothing else that they could do for him. He had to suffer in pain until he passed away on the 10th October 2021. Hurry up and pass this legislation as I do not wish someone else to suffer like my father had to. It is not nice seeing them in pain and not be able to do anything about it...”

– Survey response

The Panel considered a shorter timeframe for implementation may be achievable than was required in other States. Some aspects of the VAD scheme may be capable of immediate commencement, for example the Review Board, which could be immediately established and undertake appropriate actions in accordance with its designated functions.

The Panel considered that if future VAD legislation includes a nominated implementation period then such implementation period should be as short as practicable and not longer than 18 months.

RECOMMENDATION 22

VAD services should be ready for operational implementation within 18 months of the legislation being enacted.



7.2. Education and resources

The Panel has identified that the effective operation of VAD legislation requires the development of a sufficient level of education and resources available to practitioners, other medical staff, interpreters, patients, families and community. Guidance and information should be easily accessible, such as a website dedicated to VAD.

The provision and funding of community education to inform people of VAD is essential – not only in terms of ensuring people have the choice of access but also to address fears, concerns or misinformation. It was raised in the consultations, that some Aboriginal people may have been fearful or less likely to access hospital services when the NT Rights of the Terminally Ill legislation was in place. Concerns were expressed that if VAD is introduced this could again lead to people being fearful of accessing medical treatment.

The implementation of VAD legislation should include a focus on education – including education targeted at the broader community as well as specific identified groups. These may include Aboriginal people living in both urban and remote centres, senior Territorians, people with disabilities and other cultural groups.

Community education could be led by the NT Government VAD team, health services or not-for-profit groups. Services working with targeted groups such as AMSANT, Dementia Australia and Council on the Ageing NT, would be well placed to advise on community education strategies and content.

There should also be other mediums used to educate, and provide resources for, the general public since access to technology is not widespread in the NT. Areas for guidance might include but are not limited to the following:

- information for health practitioners and guidance on best practice
- general information for medical practitioners including roles, responsibilities, conscientious objection and how they could start providing VAD
- training/handbook for practitioners who want to become a coordinating and consulting medical practitioner. This may include topics such as general information about the training, list of modules, and videos discussing initiation, capacity to make decision, coercion, and ineligibility
- digitisation and automation of VAD assessment and request processes where possible
- quick reference guides for practitioners to understand the Act
- guides for interpreters and others who are involved in providing VAD services
- information and guides for medical practitioners when a patient is not eligible for VAD
- information and guides about care navigator service to provide information and support for VAD
- information and guides about eligibility for VAD.



08

APPENDICES



8. Education and resources

8.1. Appendix 1: Discussion Guides

8.2. Appendix 2: Terms of Reference

8.3. Appendix 3: Jurisdictions Comparator Table

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APPENDIX 1 - GUIDE 1

What is VAD and how you can have your say?

This guide may contain sensitive information related to voluntary assisted dying

Ensuring compassionate, high-quality, and accessible care for those nearing end of life, is a fundamental right for all Territorians. Just like every other Australian, the NT community should have the freedom to make choices regarding their end-of-life care. The NT has a unique history as the first jurisdiction in Australia to introduce voluntary assisted dying (VAD) in 1995. Today, many Territorians seek genuine choices for their end-of-life care, including the option to align their final moments with their held values.

VAD is a carefully regulated process that provides individuals with the choice to end their life when they wish, provided they meet all the legal criteria.

The VAD framework places a strong emphasis on safety, ethics, and the protection of both individuals and healthcare professionals. In December 2022, the Australian Senate passed the *Restoring Territory Rights Act (Cth)*, removing previous restrictions that had prevented the NT and the Australian Capital Territory (ACT) from enacting VAD legislation. VAD is already accessible in Victoria, Western Australia, Tasmania, Queensland, and South Australia, and will be introduced in New South Wales in November 2023. The ACT did also consider VAD legislation in its Legislative Assembly in 2023.

Community Engagement

An expert advisory panel has been set up as part of the consultation process. The Panel, co-chaired by Vicki O'Halloran AO CVO and Duncan McConnel CS, is committed to engaging with Territorians to gather the necessary input to shape a final report to be provided to the NT Government by July 2024. This consultation process will include regional and remote areas of the NT and major urban centres, ensuring that community questions and feedback about VAD are heard and addressed. The Panel's priority is to ensure consultation takes into account the perspectives of Aboriginal Territorians and other cultural and religious groups.

There are 5 discussion guides that are designed to assist those who want to contribute to the development of VAD legislation, regulations, and operations. They provide information about VAD in other Australian states and outline key topics for consideration and feedback across five crucial areas. The Guides also highlight the specific questions that the Expert Panel will be addressing:

1. What lessons can the NT learn from the VAD experiences in other jurisdictions, including international examples?
2. Who should have access to VAD?
3. What should be the process for individuals to access VAD?
4. What models of care should be adopted to effectively implement VAD in the NT context?
5. What are the legal and ethical responsibilities of healthcare practitioners involved in VAD?
6. What safeguards need to be established for individuals seeking or providing VAD?
7. How should compliance be monitored?
8. Any other questions that the panel deems relevant.

Stakeholders from diverse sectors across the NT, including health, non-government organisations, community groups, Aboriginal community-controlled organisations, peak bodies, universities, and researchers, will be actively engaged.

It's important to note that once the law is debated and passed, the availability of VAD to eligible individuals will not be immediate, appropriate training and protocols and processes will need to be completed and established.



APPENDIX 1 - GUIDE 2

Who should have access to voluntary assisted dying?

This guide may contain sensitive information related to voluntary assisted dying

VAD (VAD) is a process that allows eligible individuals the choice to end their life on their terms. Eligibility refers to the criteria that determines who can access VAD. We value your input on determining the criteria for eligibility and also how individuals can access and use VAD. Access to VAD should only be available to individuals who meet all the criteria.

Able to make decisions

A person's decision to access VAD must be their own and not a decision made by anyone else. However, in all Australian states that use VAD, people who have lost the ability to make decisions cannot access voluntary assisted dying.

A doctor is required to assess whether a person can make a free decision. If a doctor thinks that a person's disease or condition (for example, advanced dementia) means that a person cannot make decisions about VAD, that person will not be able to access voluntary assisted dying.

This also means that a person cannot make a decision prior to a condition or disease developing (for example, a person provides consent before they are eligible, to be assessed and access VAD after they have lost their decision making ability).

What model should we use in the Territory?

Suffering from a condition, illness or disease

In other places in Australia, a person's condition, illness or disease must be advanced, progressive or likely to cause death for a person to access VAD. In most states, the condition must also cause unbearable suffering for the person seeking VAD. In Tasmania, a person can access VAD if their condition is causing unbearable suffering, but also if their treatment is causing them unbearable suffering, or if they expect their condition or treatment will cause unbearable suffering in future.

Expected to die soon

In all Australian states, a person can only access VAD if they are likely to die within six to twelve months.

This is so a person can only access VAD if they are close to dying. Due to difficulty in estimating how soon a person is likely to die, this can also mean that a person may suffer and die before they are considered eligible to access voluntary assisted dying. In Victoria, a person can (along with additional eligibility criteria) access VAD if their disease, illness or medical condition is expected to cause death within six months (or, in the case of a person with a neurodegenerative disease, illness or condition, within 12 months).

When should an eligible person be able to access VAD in the Territory?

Living in the NT

In other places in Australia, a person must be a citizen or permanent resident of Australia to access voluntary assisted dying. Some states also allow a person who has been a resident in Australia for at least 3 continuous years to access VAD.

There are strict rules in all Australian states to ensure that people are assessed for VAD eligibility in the correct state. A person must be an Australian citizen or permanent resident, and must have resided in that state for at least 12 months before making a request to access VAD.

In some states a residency exemption may be granted if the person has a substantial connection to the state and there are compassionate grounds for granting it. This is important in cases where a person may have family or cultural connections in the NT and wants to access VAD in the NT, but lives interstate.

Age

In other parts of Australia, access to VAD is limited to adults aged 18 and above. This means that a 17-year-old meeting all eligibility criteria cannot access VAD. We are keen to hear your perspectives on how we can ensure equitable treatment for young people experiencing suffering, taking into account their decision-making capacity, and what procedures should be in place if they meet all other eligibility criteria for VAD.



APPENDIX 1 - GUIDE 3

What process should a person follow to access VAD

This guide may contain sensitive information related to voluntary assisted dying

Territorians should have access to appropriate information and support to help them make decisions about accessing VAD (VAD).

What do you think the process should be for accessing VAD in the NT?

For your consideration, this is a summary of the process to access VAD in other Australian states:

1. The person asks a qualified and experienced doctor (first doctor) to help with voluntary assisted dying.
2. The first doctor assesses if that the person is eligible to access voluntary assisted dying.
3. The person asks a different qualified and experienced doctor (second doctor) to help with voluntary assisted dying.
4. The second doctor assesses that the person is eligible to access voluntary assisted dying.
5. The person makes a written request to the first doctor, witnessed by independent witnesses.
6. The person makes a final request to the first doctor.
7. The first doctor makes sure the person is still eligible for voluntary assisted dying, submits paperwork, and arranges for a pharmacist to supply a prescribed VAD substance.
8. The person dies by taking the VAD substance when they choose to do so, either by taking the substance themselves or by asking a health professional to help them take the substance.

Finding a health professional who can help

In the Territory with small populations spread out over a large area, it can be hard to find a doctor. Online meetings are often the only way people can speak to health professionals.

How should Territorians be able to request access to voluntary assisted dying, and should they be allowed to use online platforms, for example, the first request must be in person with a health professional, but the second request can be online?

In other Australian states, a nurse practitioner can also help a person access VAD, should we consider this in the NT?

Making sure Territorians freely choose VAD In other places in Australia, a person can only access VAD if they take a few days to think about it before making the final request. A person can

only access VAD if other people witness at least one written request and a witnesses must be someone who will not benefit personally or financially from the person's death.

Do you think a person can be a witness for a VAD request if they are also a beneficiary?

In some places in Australia, a medical professional is not allowed to start a discussion about VAD. Other states allow medical professionals to start the discussion about VAD, but they must provide information about treatment, palliative care and support options and their likely outcomes at the same time.

What model should we use in the NT?

Taking the VAD substance to die

In parts of Australia, a doctor can provide an eligible person access to a prescribed medication to bring about the person's death as part of the VAD process. This substance is called the VAD substance.

The person can decide when, or even if, they want to use this substance. Some states have established specific timeframes for returning the substance if the individual opts not to use it (e.g., within seven days).

In most Australian states, individuals are required to self-administer the VAD substance, but in cases where this isn't possible or appropriate, a doctor can assist them. Some states also allow individuals the choice of self-administration or seeking assistance from a healthcare professional. How should we approach this in the NT?

Notifying and registering a person's death

When a person dies in the NT, it must be registered with Births, Deaths and Marriages within seven working days after the burial or the cremation.

A death registration statement is usually completed by the funeral director, the person who arranges for the disposal of the remains, or a local health worker. Death certificates are used for various legal, insurance and other purposes and a person's family might not want to include details of how a person died. Some states in Australia require a death certificate to state that a person's death was caused by their illness, and not caused by voluntary assisted dying.

We want to know your views on how a person's death should be notified and registered if they die from voluntary assisted dying.



APPENDIX 1 - GUIDE 4

The role of health professionals and health services

This guide may contain sensitive information related to voluntary assisted dying

What role should health professionals play in the VAD process, and what safeguards should be in place to protect health professionals and their patients?

Helping a person through the VAD process

In other places in Australia, a person seeks help from a health professional before they can access VAD and a health professional must have the right training to help someone through the VAD.

In the NT, we also need to consider how people in regional, remote and very remote areas can access health professionals who can guide a person through the VAD process.

In other places in Australia, a doctor (meaning a general practitioner or medical specialist) can assess whether a person can access VAD and help them through the process and to assess a person, the doctor must complete VAD training and have a minimum level of experience and skills. For example, a doctor must have five years' experience to be able to assess a person. Some states say a doctor must have expertise or be a specialist in treating the person's illness.

The Territory has a small population spread over a large area, so there might not be many doctors that could help with VAD, especially in regional and remote areas. If it is difficult to find a doctor, some people who are eligible, might not be able to access voluntary assisted dying.

We want to know if other types of health professionals with the right skills and experience, such as nurse practitioners, should be able to help a person throughout the VAD process.

Talking to a person about voluntary assisted dying

Should a health professional be allowed to start a conversation with a person about voluntary assisted dying?

In some Australian states, health professionals are not allowed to start a conversation about VAD with their patients. The person considering VAD must start the conversation themselves.

Accessing VAD must be

a person's free choice. However, if a health professional cannot start a conversation about VAD with their patients, this can make it difficult to provide patients with information about all of their end of life options.

The VAD substance

We want to know your views on what responsibilities a health professional should have in relation to a VAD substance.

A VAD substance is a medication prescribed by a doctor to cause a person's death at the end of the VAD process. Health professionals help make sure a VAD substance is not available to a person until the person is assessed as eligible and has followed the required process.

In other states in Australia, health professionals have various roles and responsibilities:

- A VAD substance can only be prescribed by a doctor.
- When prescribing a VAD substance to a person, the doctor must provide the person with information and report to an independent monitoring agency.
- A VAD substance can only be provided by a pharmacist, and sometimes the pharmacist must have extra training and approval.
- When providing a VAD substance to a person, a pharmacist must give the person information and warnings, and sometimes must verify the person's identity to make sure the substance is provided to the right person.
- A health professional can help the person to use the substance when they are ready if it is not possible or not appropriate for a person to use the substance themselves.

If health professionals follow the law, they should be able to help with VAD without fear of unintentionally committing a crime. We want to know your views on how we can protect health professionals who are involved in voluntary assisted dying, but also make sure there are serious consequences for people who do the wrong thing.



APPENDIX 1 - GUIDE 4

The role of health professionals and health services cont.

Health professionals who do not want to help with voluntary assisted dying

Some health professionals might not want to help with VAD because it is not their area of expertise, they are not available or they conscientiously object to voluntary assisted dying. Conscientious objection is when a health professional doesn't want to be involved with VAD because their personal, cultural, or religious beliefs do not support the concept of VAD. In other places in Australia, health professionals are allowed to have a conscientious objection and not help a person with voluntary assisted dying.

We want to know your views on how to protect the rights of health professionals to uphold their beliefs, while also protecting people who want to access voluntary assisted dying.

The role of health services in voluntary assisted dying

How should a person access VAD if they are living or staying at a health facility or community service, such as hospitals, palliative care hospices, or aged care homes?

People who want to access VAD are often living or staying at a health facility. Some health facilities don't support VAD or allow access to VAD. This may be because of faith-based beliefs

Some states in Australia have not stated the role of health and community facilities in their VAD laws and have instead provided guidance for these services.

Other places have made laws that health facilities and community services must not prevent a person from accessing VAD at a facility where they live or stay. Health facilities and community services must allow health professionals to visit to help a person through the VAD process. If this is not possible, the service must transfer a person to a place where they can access voluntary assisted dying.

There are different rules for people who live permanently at a health or community facility, for example, an aged care home, and people who stay temporarily at a health facility or community service such as a hospital. Some states also

require health services to put information on their website that informs the public about their views on voluntary assisted dying.

How should we approach this in the NT?



APPENDIX 1 - GUIDE 5

Monitoring and compliance - How should we monitor VAD to make sure the process is safe and effective?

This guide may contain sensitive information related to voluntary assisted dying

We want to know your views on how we can make sure VAD has the right safeguards for individuals and health professionals in the NT.

Reporting by health professionals

What should health professionals be required to tell us about their role in helping a person with voluntary assisted dying?

In other Australian states, health professionals are required to provide information at every stage of the VAD process to make sure health professionals are complying with the law. It can also provide information to assess how VAD is working in the community. For example, when a person tells a health professional that they want to access voluntary assisted dying, or when a health professional helps a person to use a VAD substance to die, health professionals are required to submit forms that record each step.

Checking that health professionals are following the law

How should we check that health professionals are following the law in the NT?

In some states in Australia, an independent body reviews each report submitted by a health professional, and a person must not progress to the next step of the VAD process until the agency approves the report. This can be a thorough process that closely checks that people are following the law, but it can also slow down the process and make it harder for a person to access voluntary assisted dying.

In other states, an independent body only reviews the reports submitted by a health professional every few weeks or months. In this instance, there is no need for a health professional to wait for approval to move to the next stage of the VAD process.

Reviewing eligibility decisions

Do you think a health professional's decision about whether a person is or is not eligible to access VAD should be able to be reviewed by a tribunal, court or other body?

Consequences if someone breaks the law

What should the consequences be if a person breaks laws about VAD in the NT?

Other Australian states have made it a crime for:

- a health professional to submit false reports about voluntary assisted dying

- a health professional to fail to submit reports about voluntary assisted dying
- a health professional who breaches any part of the VAD legislation
- anyone to help a person use a VAD substance outside of the lawful VAD process
- anyone to dishonestly convince a person to use a VAD substance.

Some states also allow a person to notify the Australian Health Practitioner Regulation Agency if they have concerns about a health professional, or believe a health professional has broken the law. This is the agency that makes and enforces rules about certain types of health professionals.

Protecting people from misusing a VAD substance

We want to know how you think we can protect people from misusing a VAD substance in the NT.

A VAD substance is medication prescribed by a doctor to cause a person's death. We need safeguards to protect our community and ensure the substance is handled with extreme care and caution, and is not misused. We also want to avoid barriers that make it too hard for a person to use the substance when they are eligible and ready.

Other states in Australia do this by:

- requiring health professionals and pharmacists to provide information about the substance
- requiring health professionals and pharmacists to give warnings to the person about the substance
- requiring pharmacists to complete forms and keep records
- requiring the substance to be kept in a locked box
- requiring any unused substance to be returned and destroyed within a set timeframe
- making it a crime to misuse or mishandle the substance.

Some states in Australia also require health professionals to apply for and receive a permit to arrange the VAD substance, require pharmacies to be authorised, and require pharmacists to verify and record a person's identity.

Should we use this approach in the Territory?



APPENDIX 2

Terms of reference - Expert Advisory Panel

VAD legislation in the NT

This guide may contain sensitive information related to voluntary assisted dying

Expert Advisory Panel

Background

The provision of compassionate, high quality and accessible palliative care for persons at their end of life is a fundamental right for everyone living in the NT. The NT community is entitled to make choices to manage their end of life care, as are all other Australians.

The NT was the first jurisdiction in Australia to introduce VAD (VAD) with the Rights of the Terminally Ill Act 1995 (NT) (the ROTI Act).

The ROTI Act involved a lengthy application process to determine mental competence and a terminal illness. It required assessment by three independent medical practitioners including a specialist to confirm the terminal nature of the illness and a psychiatrist to confirm the patient was not clinically depressed. It was followed by a nine day 'cooling off' period.

Four people with terminal conditions accessed the legislation and were supported through VAD. These people were also able to access palliative care services from the Department of Health.

The effect of the law was overridden in 1997 by the passage of the Euthanasia Laws Act 1997 (Cth). The Commonwealth legislation amended the NT (Self-Government) Act 1978 (Cth) by removing the NT Legislative Assembly's power to make any law permitting euthanasia. The Commonwealth legislation also removed this power from the Legislative Assemblies of the Australian Capital Territory (ACT) and Norfolk Island.

Current situation

The ROTI Act remains in force but with no legal effect. On 1 December 2022, the Senate passed the Restoring Territory Rights Act 2022 (Cth) which repealed the 1997 amendments meaning the NT can now enact modern legislation to allow VAD.

All other Australian state jurisdictions have enacted or are developing modern VAD legislation customised to their community, with Victoria's law operating since 2019. The ACT is currently progressing with their legislation, having completed a public consultation process ahead of reporting back to the ACT Legislative Assembly for the introduction of a Bill in late 2023. VAD is now a standard treatment option throughout Australia and in many other countries.

The laws around Australia are similar, with criteria for eligibility, including being over the age of 18 years, being an Australian citizen or permanent resident, having competent decision-making capacity, and having a life-limiting illness. Criteria vary between jurisdictions on the definitions of eligible diseases or medical conditions, and the process for assessment and administration.

The NT will now embark on an extensive consultation process to listen to the views of our community, address concerns, and develop safeguards so that Territorians can make informed choices about their end of life.

Governance of the Consultation

An independent Expert Advisory Panel (the Advisory Panel) will be commissioned to lead the consultation process under the Inquiries Act 1945.

The Advisory Panel will be co-chaired by eminent persons with specific knowledge of the NT. Panel members will be selected based on their expertise in the fields of end of life health care, Aboriginal and Torres Strait Islander cultural matters, justice, and social welfare policy.

The Advisory Panel will advise on the development of a discussion paper, lead the consultation process and make recommendations for the potential development of VAD legislation.

The Advisory Panel will report to the Chief Minister.

Terms of Reference

The Advisory Panel is tasked with providing advice to Government to assist in the consultation and potential development and implementation of a new statutory framework for VAD.

Specifically, the Advisory Panel will provide advice to the Government on an appropriate legal framework for VAD in the NT by answering the following questions:

- i. What can the NT learn from the VAD experience in other jurisdictions, including overseas?
- ii. Who should be able to access VAD?
- iii. What process should a person follow to access VAD?
- iv. What models of care should be adopted so that VAD can effectively be delivered in the NT context?
- v. What are the legal and ethical obligations of Health Practitioners who provide services relating to VAD?



- vi. What safeguards need to be put in place for those accessing or providing VAD?
- vii. How should compliance be monitored? and
- viii. Any other question the panel considers appropriate.

The Panel must report on its findings to Government by end of July 2024.

Discussion guides

To inform the community-wide discussion and to provide guidance for those wishing to provide feedback and input into the consultation process, a number of Discussion Guides (the Guides) will be released. The Guides will outline a range of health, social, community, and legal issues to be addressed by the consultation process.

The Guides will include information on VAD, possible eligibility and processes, and pose questions to seek input from the public on ideas, concepts and types of measures that could be adopted to ensure any VAD legislation is suited to our community.

Consultation

Broad public consultation will be undertaken, with multiple avenues for interested people and groups to put forward their views, which may include the following:

- a dedicated website
- an online survey
- public meetings in the major centres
- meetings with key stakeholders
- meetings with community groups
- written submissions
- any other methods as considered appropriate by the Panel.

Wherever possible, consultation will be undertaken with the assistance of appropriate interpreters.

Timing of the consultation

This is a crucial piece of public policy, with the potential to reshape end of life outcomes for Territory individuals, families, and communities.

The Panel will commence its work in late 2023.

Public consultation will occur through to the end of April 2024, enabling the preparation of a report with recommendations to Government by the end of July 2024.



APPENDIX 3

Jurisdiction's Comparator Table

	VIC	WA	TAS	SA	QLD	NSW	ACT
Start date	19 June 2019	1 July 2021	23 October 2022	31 January 2023	1 January 2023	28 November 2023	3 November 2025
Disease, illness or medical condition is expected to cause death within a specified timeframe (six months, 12 months for neuro-degenerative disease)	✓	✓	(Ability to apply for an exemption to the commission)	✓	(Will "most likely" cause death within timeframe)	(Will "on the balance of probabilities" cause death within timeframe)	✓
Disease, illness or medical condition is expected to cause death within a specified timeframe (six months, 12 months for neuro-degenerative disease)	✓	✓	✓	✓	✓	✓	X
Voluntary assisted dying not suicide	X	✓	✓	✓	✓	✓	✓
Person has decision-making capacity in relation to assisted dying	✓	✓	✓	✓	✓	✓	✓
Mental health as sole diagnosis allowable	X	X	X	X	X	X	X
18 years or older	✓	✓	✓	✓	✓	✓	✓
All criteria must be met	✓	✓	✓	✓	✓	✓	✓
Patient or practitioner can administer the VAD substance	X Self-administration is the default)		X (Self-administration certificate required)	(Application may be made for a practitioner administration permit)	(Can only choose practitioner administration if self-administration is inappropriate)	✓	✓
Nurse practitioner allowed to administer the voluntary as-sisted dying substance	X	✓	✓	✓	✓	✓	✓
Telehealth allowed	X Not specifically allowed)	✓	X Not specifically allowed)	X Not specifically allowed)	X	✓	X Not specifically allowed)
Medical practitioner allowed to initiate discussion about assisted dying	X (Must respond to request in 7 days, do not need to provide information)	✓	X (Must respond to request in 7 days, do not need to provide information)	X (Do not need to provide information)	X (Required to provide details of navigator service)	X (Must respond to request in 7 days, do not need to provide information)	X (Must provide the contact details for the care navigator service within 2 business days)

	VIC	WA	TAS	SA	QLD	NSW	ACT
Medical assessment needed	✓	✓	✓	✓	✓	✓	✓
Entity may refuse voluntary assisted dying service delivery	✓	✓	✓	X	✓	X	X
Must be a resident in the jurisdiction	✓	✓	✓	✓	✓	✓	✓
Suffering cannot be relieved in a manner the person considers tolerable	✓	✓	✓	✓	✓	✓	✓
Medical practitioners must notify the patient of conscientious objection immediately	X (Must respond to request in 7 days, do not need to provide information)	✓	X (Must respond to request in 7 days, do not need to provide information)	X (Do not need to provide information)	X (Required to provide details of navigator service)	✓	X (Must provide the contact details for the care navigator service within 2 business days)
Coercion prevention - Person must make three requests. One request must be in writing. There must be two witnesses to the written request.	✓	✓	✓	✓	✓	✓	✓
Review by tribunal of some criteria (e.g. reviews of resi-dency, decision making ca-pacity, or voluntariness)	✓	✓	✓	✓	✓	✓	✓
Waiting period between first and final requests	✓	✓	✓	✓	✓	✓	X
Person may withdraw re-request at any time	✓	✓	✓	✓	✓	✓	✓
Referral to another medical practitioner if eligibility can-not be determined (e.g. un-certainty about a person's diagnosis or decision making capacity)	✓	✓	✓	✓	✓	✓	✓
Medical practitioners must complete training before assessing person	✓	✓	✓	✓	✓	✓	✓
Medical professionals must report at points throughout the assisted dying process	✓	✓	✓	✓	✓	✓	✓



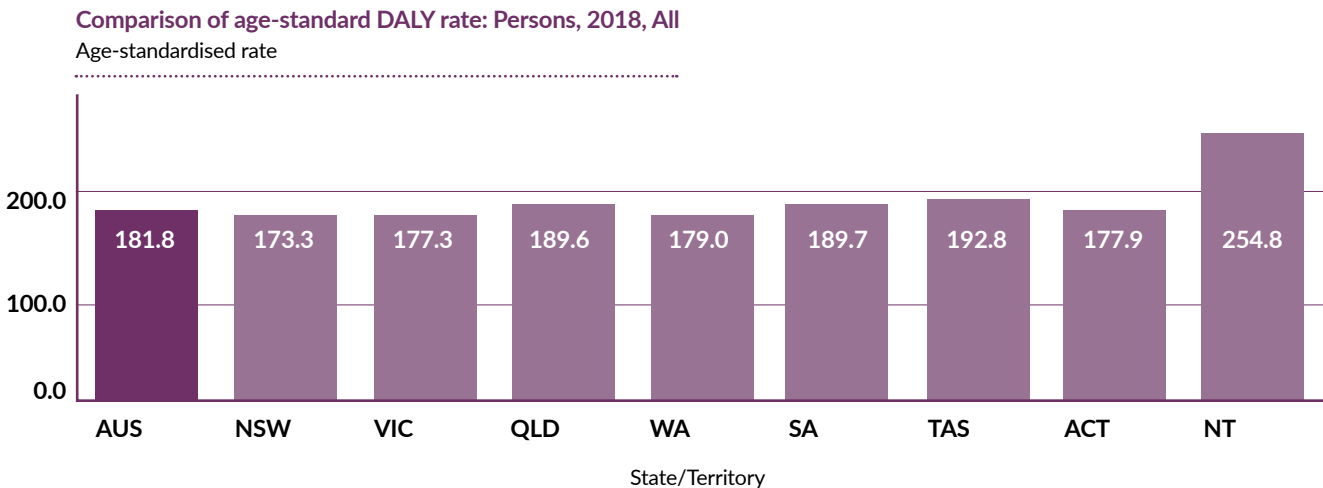
APPENDIX 4

Burden of Disease in the NT - Comparison with other jurisdictions

The NT has a unique disease profile in comparison to the rest of Australia. A commonly used health statistic that can be used to quantify population health is the disability-adjusted life year, or DALY, used to measure burden of disease. This measures the gap between a population's 'ideal' health, where everyone lives in full health to an ideal age, and their actual health. The DALY is a composite measure, combining health loss from living with illness and injury (non-fatal burden, or YLD) and dying prematurely (fatal burden, or YLL) to estimate total health loss, or burden of disease. 1 DALY is equivalent to 1 year of healthy life lost. The Australian Burden of Disease Study 2018, published in 2021, provides the most recent Australian-specific estimates of disease burden.

The following graph, taken from the study, provides an age-standardised DALY rate, or the burden of disease per 1000 population. Age-standardisation allows this metric to be compared across populations with different age structures, such as Aboriginal and non-Aboriginal populations. The graph shows that the NT has the highest burden of disease of any Australian jurisdiction, at 254.8 DALYs per

1000 population, compared to an Australian average of 181.8 DALYs per 1000 population. The total burden of disease is 40 per cent greater in the NT compared to the national average.



Regarding specific disease groups, the NT grapples with a 36 per cent higher burden of disease rate related to cancer and other neoplasms compared to the national average. This holds particular significance in the context of voluntary assisted dying, as a majority of individuals opting for VAD have cancer as their life-limiting condition in other Australian jurisdictions.

In addition, the NT has significantly higher burden of disease rates of certain chronic diseases, with approximately twice the national average for cardiovascular disease, and over twice the national average for kidney diseases, blood and metabolic disorders, endocrine disorders and infectious diseases. Poorer health outcomes among Aboriginal people contribute to this discrepancy.

Aboriginal people constitute around 70 per cent of consumers in NT public hospital services, emerging as a substantial health consumer group for NT Health. DALY rates within the Aboriginal population are consistently higher across all disease categories compared to the non-Aboriginal population. The most significant disparities are observed in endocrine disorders, with 13.5 times higher rates, and kidney diseases, with 11.4 times higher rates, respectively, than non-Aboriginal Territorians.

Between 2011 and 2015 Aboriginal people made up nearly two-thirds of deaths in the NT from chronic diseases (including cancer, diabetes, and respiratory diseases). Poor health outcomes are influenced by social and cultural determinants of health, including social disadvantage, poverty and low levels of health literacy. These markers of social disadvantage are all higher among Aboriginal Territorians compared to their non-indigenous counterparts. These factors contribute to higher rates of poor health and mortality compared to non-Aboriginal Territorians. Living in remote and very remote areas also correlates with a higher burden of disease, with rates in these areas being 1.4 times as high as in major cities, another important determinant of health.

APPENDIX 4

Burden of Disease in the NT - Comparison with other jurisdictions (Cont.)

Caring for and managing older Aboriginal individuals over the long term is becoming progressively challenging. The aging population and advancements in life expectancy are expected to lead to substantial growth in the older Aboriginal age cohorts. By 2041, the proportion of older Aboriginal individuals is forecasted to almost triple, introducing further complexities for diverse services such as dementia care, aged care, opportunities for aging 'on country,' and access to palliative care services. VAD adds a further dimension to those challenges, generating potential social, economic and political risks for overall service delivery related to the disease burden in the NT, particularly in the nonurban setting.

Implications of burden on disease for accessing voluntary assisted dying

There are many factors relating to the disease burden in the NT that the Panel considers will influence accessing VAD in the NT.

The Panel considered the data on the number of people who have sought VAD in other jurisdictions, their circumstances and the life-limiting illness from which they suffered.

Data from around Australia shows that a significant portion of people considering or accessing VAD have a cancer diagnosis as their life-limiting condition. The Panel considers this would be consistent in the NT due to the NT having a 36 per cent greater burden of disease rate from cancer and other neoplasms compared to the national average.

As noted above, there is a significantly higher burden of disease rates for chronic conditions in the NT compared to the national average. This indicates that, if legislated, individuals seeking VAD in the NT may have non-cancer diagnoses as their life-limiting condition and reason for accessing voluntary assisted dying. Non-cancer diagnoses, outside of neurological disorders, have not commonly been the stated life-limiting illness in other jurisdictions and this unique feature of the NT's population requires careful consideration.

The significantly higher burden of disease rates for Aboriginal populations indicates that, if legislated, individuals seeking to access VAD may be Aboriginal. The centrality of culture to health implies that VAD services should be culturally safe and respectful of Aboriginal cultures. In making recommendations for VAD legislation in the NT, cultural consultation is essential in recognising and being respectful of cultural values around voluntary assisted dying.



APPENDIX 5 - GUIDE

Discussion paper on VAD - Summary of the key clinical issues

This guide may contain sensitive information related to voluntary assisted dying

Context

The NT Government is undertaking consultation to consider legislating for VAD (VAD) in the NT, led by an Expert Advisory Panel.

The process of VAD has profound consequences for end-of-life patients, their families, healthcare providers, and the broader community.

Maintaining a balance between personal autonomy and appropriate safeguards is a central theme of the Expert Advisory Panel's Terms of Reference. We are seeking views from key clinical stakeholders about how best to achieve this balance. This information guide has been developed to promote discussion and generate suggestions, which consider the unique service delivery challenges, cultural and geographic context of the NT. Your input will help inform the Panel's recommendations to the Government.

An overview of the VAD process in Victoria is available as a separate sheet. Existing approaches in other Australian jurisdictions form the starting point for these deliberations in the NT.

PART A: ELIGIBILITY

Existing VAD legislation nationally limits eligibility to advanced, progressive and incurable conditions, to patients with capacity, and to suffering that is unable to be relieved in a manner that the person considers tolerable.

Prognosis

QLD 12 months all conditions

ACT Proposed no prognosis limit

OTHER STATES Six months; 12 months if it is a neurodegenerative disease

Discussion points

- Prognostication is an inexact science, especially with non-cancer diagnoses (CCF, COPD).
- A six-month time frame has caused significant stress for patients in other states. Accessibility of clinicians in the NT may exacerbate this issue locally.
- Allowing access to self-administered VAD over a longer prognostic period (e.g. 12 months) may have unintended consequences of VAD substances being held in the community for longer periods.
- Excluding prognostic criteria may minimise 'doctor shopping,' where patients seek a prognosis to achieve their ends.

Nationally, VAD is not available to those under 18 nor is it able to be included within an advanced care directive. People with mental health as a sole diagnosis are ineligible.

Initiation of VAD discussion

SA Discussion can only be initiated by patients, with **VIC** clinicians not to initiate – the 'gag clause'

WA Medical practitioner can initiate conversation, must **TAS** also offer other options, including palliative care

QLD As for WA and Tasmania but nurse practitioners **NSW** may also initiate conversations.

ACT As for QLD and NSW, but any health professional may also initiate conversations, as long as they refer the patient to their treating doctor.

The "gag clause" has been debated widely.

Discussion points

- Pros: Discussion of VAD may be misinterpreted as a recommendation for VAD. In the NT, the power imbalance between doctors and patients is even more significant when First Nations patients' issues with health services are considered
- Cons: less accessible for those with less health literacy or from CALD backgrounds, goes against principles of informed consent

PART B: MODELS OF CARE

There are two centralised components to service delivery in all jurisdictions. VAD Care Navigator services consist of nursing and allied health professionals with experience in end of life care who manage queries related to voluntary assisted dying, facilitate connections between services, and support referrals to participating medical practitioners. A centralised pharmacy service is responsible for medication management.

There is a concurrent decentralised model of medical service provision. Patients find their own medical practitioners, who can be working in public hospital positions or privately. Medical practitioners are responsible for completing VAD training.



Proposed service delivery models in the NT

Option 1: A fully centralised service - with regional offices in the large centres physically and administratively separate from existing health facilities. Doctors, pharmacy services and Navigators would be employed directly through the service, and VAD to only be provided by this service.

This ensures that VAD services are easy to find and identify, reduces the risk of confusion and “contamination by association” of a health service being co-located with a VAD provider.

Option 2: A mainly decentralised service, as in other jurisdictions. This would involve funded Navigator positions in each region to assist people requesting VAD to identify which practitioners are available locally who can manage the assessment and administration of VAD. Pharmacy services can also be devolved, with involvement of community pharmacies. In the NT, this option would be challenging, due to limited availability of workforce outside of Darwin and Alice Springs.

Workforce

The assessment process focuses on the applicant’s clinical eligibility (diagnosis and prognosis), competence to make the decision, and ensuring the decision is voluntary, sustained, and without coercion. There must be a co-ordinating and a consulting practitioner for each patient, and there may also be an administering practitioner.

VAD provider roles

Coordinating practitioner	Coordinates process for patient Assessment of eligibility Prescribes VAD substance
Consulting practitioner	Independently assesses eligibility
Administering practitioner	Administers VAD substance if appropriate

All jurisdictions require coordinating and consulting practitioners to be doctors, with the exception of the ACT below. Specialist registration is required for both, with additional experience of one, five or ten years post Fellowship, depending on state, except Tasmania, in which the only requirement is a medical Fellowship. WA has extra provisions for overseas trained specialists. Vic, Tas and SA require one of the doctors to have specific expertise in relation to the patient’s condition.

Nurse practitioner roles

Coordinating practitioner	Coordinates process for patient Assessment of eligibility Prescribes VAD substance
Consulting practitioner	Independently assesses eligibility
Administering practitioner	Administers VAD substance if appropriate

Discussion points

- There are concerns for the NT about timely access to practitioners who will be willing and eligible to participate in VAD assessments.
- Availability of experienced GPs who are willing and able to be involved may be less than in other states. Nurse practitioners are much less available in the NT than in other jurisdictions.

- In other jurisdictions, there is already an evolving experience that a small number of clinicians are involved, with escalating demand. This carries personal, professional and clinical risks for them, as well as likelihood of burnout. The risks are particularly high for sole practitioners without formal support.
- Within smaller communities, the problems for clinicians of being closely associated with VAD may be significant, and may limit the number of doctors who are willing to be involved
- Other skilled professional groups could be considered specifically for the role of administering practitioner, for instance those who have trained as paramedics, which might increase the pool of locally available VAD providers.

Nurse practitioner roles

Conscientious objection is the personal objection or refusal by clinicians and others to participate in the process by which a person identifies and seeks access to VAD. All jurisdictions allow conscientious objection. There are two aspects to conscientious objection in other states.

- The ability of clinicians and others to decline to be involved in some or all aspects of providing VAD. In Qld and the ACT clinicians must provide information about the VAD navigator service if requested. In WA and NSW they must inform the person immediately that they are conscientious objectors.
- Health services or other facilities (e.g. nursing homes) may have an institutional objection to VAD provision. SA, Qld and NSW allow institutional objections within their legislation, but define the responsibilities of those institutions to ensure access to VAD.

Nurse practitioner roles

- In the NT, there may be cultural concerns from both individuals and health services, that being associated with the provision of VAD may significantly damage the trust of Aboriginal and Torres Strait Islander users of those services.

APPENDIX 6 - Consultations

Organisations consulted

	Date	Consultation	Location
1	4 September 2023	NT Probus	Darwin
2	6 September 2023	Southern Cross Care	Darwin
3	11 September 2023	NT Aids & Hepatitis Council	Darwin
4	13 September 2023	NT Council of Social Services	Darwin
5	16 September 2023	St John Ambulance NT	Darwin
6	11 October 2023	St John Ambulance NT	Katherine
7	11 October 2023	Katherine Town Council	Katherine
8	12 October 2023	Katherine Hospital	Katherine
9	12 October 2023	Rocky Ridge Nursing Home	Katherine
10	21 October 2023	National Seniors Top End	Darwin
11	9 November 2023	University of 3rd Age	Darwin
12	15 November 2023	Ngurratjuta/Pmara Ntjarra Aboriginal Corporation	Alice Springs
13	15 November 2023	Aboriginal Medical Services Alliance NT	Alice Springs
14	16 November 2023	ALOS & APUS	Alice Springs
15	16 November 2023	Alice Springs Hospital	Alice Springs
16	16 November 2023	Palliative Care NT	Alice Springs
17	16 November 2023	Oncology/Palliative Care	Alice Springs
18	17 November 2023	Central Desert Regional Council	Alice Springs
19	17 November 2023	Alice Springs Town Council	Alice Springs
20	17 November 2023	Remote Medical Practitioners	Alice Springs
21	22 November 2023	Gundjeihmi Aboriginal Corporation	Jabiru
22	22 November 2023	West Arnhem Regional Council	West Arnhem
23	23 November 2023	Red Lily Health Board	Jabiru
24	28 November 2023	Gove District Hospital	Gove
25	29 November 2023	Miwatj Aboriginal Corporation	Darwin

APPENDIX 6 - Consultations

Organisations consulted cont.

	Date	Consultation	Location
26	30 November 2023	Speech Pathology Australia	Darwin
27	5 December 2023	Central Australian Aboriginal Congress	Alice Springs
28	11 January 2024	NT Voluntary Euthanasia Society	Darwin
29	11 January 2024	Australian Regional and Remote Community Services	Darwin
30	17 January 2024	NT Health	Darwin
31	18 January 2024	NT Primary Health Network	Darwin
32	1 February 2024	Rotary Club of Darwin	Darwin
33	9 February 2024	Catholic Church Diocese	Darwin
34	13 February 2024	The Royal Australasian College of Physicians	Darwin
35	14 February 2024	Aboriginal Community Controlled Health	Darwin
36	19 February 2024	Royal Darwin and Palmerston Hospitals	Darwin
37	6 March 2024	Barkly Aboriginal Alliance	Tennant Creek
38	20 March 2024	Australian Christian Lobby	Darwin
39	3 April 2024	NT Disability Advisory Committee	Darwin
40	16 April 2024	South Australian VAD Team	Darwin
41	9 May 2024	Tennant Creek Hospital	Tennant Creek
42	9 May 2024	Tiwi Islands service providers	Online
43	9 May 2024	Aboriginal Health Practitioners	Tennant Creek
44	9 May 2024	Barkly Aboriginal Backbone	Tennant Creek
45	10 May 2024	Urapunjta Health	Tennant Creek
46	13 May 2024	2M Language Services Queens-land	Darwin
47	23 May 2024	NT Coroner	Darwin

APPENDIX 6 - Consultations

Community consultations

	Date	Region	Location
1.	11 October 2023	Big Rivers	Katherine
2.	19 October 2023	Top End	Darwin City
3.	1 November 2023	Top End	Marrara
4.	9 November 2023	Top End	Palmerston
5.	16 November 2023	Central Australia	Alice Springs
6.	28 November 2023	East Arnhem	Nhulunbuy
7.	12 February 2024	Top End	Casuarina
8.	18 March 2024	Top End	Casuarina
9.	29 April 2024	Top End	Wadeye
10.	9 May 2024	Barkly	Tennant Creek



APPENDIX 6

Submissions

	Date	Region
1	11 October 2023	Individual
2	17 October 2023	Individual
3	18 October 2023	Individual
4	19 October 2023	Individual
5	26 October 2023	End of Life Choice Society New Zealand
6	10 November 2023	Individual
7	10 November 2023	Individual
8	14 November 2023	NT Education Union
9	19 November 2023	Individual
10	4 December 2023	Individual
11	5 December 2023	Australian Medical Association Territory Inc.
12	7 December 2023	Individual
13	7 December 2023	Individual
14	12 December 2023	VAD South Australia
15	18 December 2023	The CLEM Jones Group
16	20 December 2023	Individual
17	8 January 2024	NT Voluntary Euthanasia Society
18	11 January 2024	Australian Care Alliance
19	15 January 2024	Individual
20	1 February 2024	Individual
21	1 February 2024	Living and Dying Well
22	1 February 2024	Palliative Care NT
23	5 February 2024	Family Voice Australia
24	6 February 2024	Individual
25	7 February 2024	Individual
26	7 February 2024	Individual
27	7 February 2024	Individual
28	8 February 2024	Individual

	Date	Region
29	8 February 2024	Individual
30	8 February 2024	Dementia Australia
31	8 February 2024	Individual
32	8 February 2024	Individual
33	8 February 2024	Individual
34	9 February 2024	Individual
35	9 February 2024	Individual
36	9 February 2024	Australian Psychological Society
37	12 February 2024	Individual
38	12 February 2024	Individual
39	12 February 2024	Individual
40	13 February 2024	Individual
41	13 February 2024	Australian Centre for Health Law Research
42	14 February 2024	Individual
43	14 February 2024	The Right to Life Australia
44	15 February 2024	Online
45	16 February 2024	Individual
46	16 February 2024	Individual
47	16 February 2024	Go Gentle
48	16 February 2024	Individual
49	16 February 2024	Australian Lawyers Alliance
50	16 February 2024	Individual
51	16 February 2024	Individual
52	17 February 2024	Individual
53	19 February 2024	Australian Christian Lobby
54	19 February 2024	Individual
55	20 February 2024	Individual
56	20 February 2024	Individual

APPENDIX 6

Submissions

	Date	Region
57	21 February 2024	The Royal Australian and New Zealand College of Psychiatrists
58	21 February 2024	Individual
59	21 February 2024	Individual
60	22-25 February 2024	Individual
61	24 February 2024	Individual
62	24 February 2024	Individual
63	25 February 2024	Individual
64	26 February 2024	Individual
65	26 February 2024	Individual
66	28 February 2024	Individual
67	28 February 2024	Cherish Life Organisation
68	28 February 2024	Dying with Dignity Victoria Inc.
69	29 February 2024	Dying with Dignity New South Wales
70	29 February 2024	Individual
71	29 February 2024	Individual
72	1 March 2024	Exit International
73	1 March 2024	The Royal Australasian College of Physicians
74	1 March 2024	Individual
75	1 March 2024	Parliament of New South Wales
76	1 March 2024	Northern Synod of the Uniting Church in Australia
77	1 March 2024	Canberra Declaration Organisation
78	1 March 2024	Individual
79	5 March 2024	Individual
80	6 March 2024	Individual

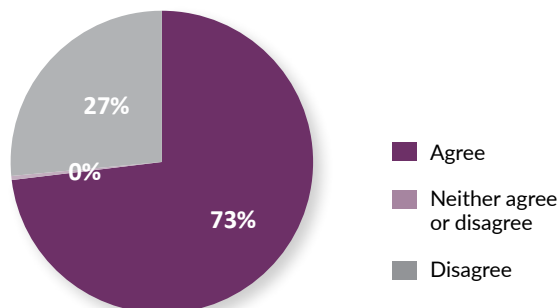
	Date	Region
81	7 March 2024	Individual
82	19 March 2024	Dying with Dignity Western Australia
83	27 March 2024	Australian Doctors Federation
84	18 April 2024	Individual
85	19 April 2024	Multicultural Council of the NT
86	24 April 2024	NT Health – Medical Management Team
87	29 April 2024	Central Australian Aboriginal Congress
88	29 April 2024	Individual
89	30 April 2024	Catholic Darwin Diocese
90	30 April 2024	Aboriginal Medical Services Alliance NT
91	1 May 2024	Individual
92	1 May 2024	Women’s Forum Australia
93	1 May 2024	Pro-Life Victoria
94	9 May 2024	Public Guardian and Public Trustee
95	28 June 2024	Individual
96	28 June 2024	Individual
97	1 July 2024	Individual



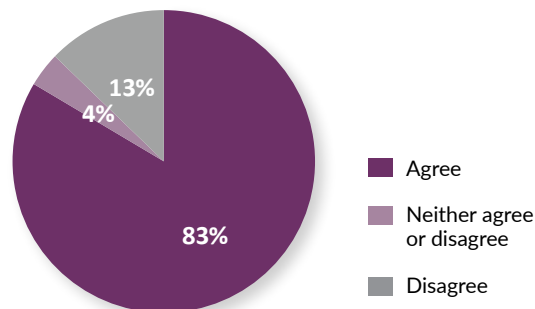
APPENDIX 7

Online survey results

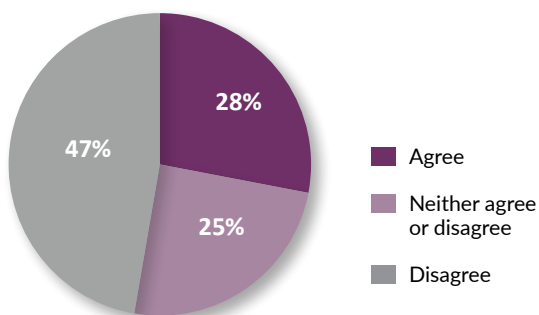
A person should be able to choose when they die



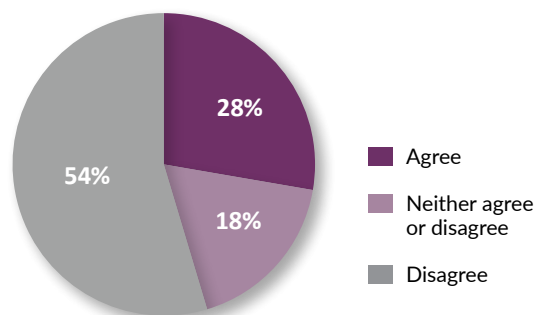
A person should be able to choose where they die



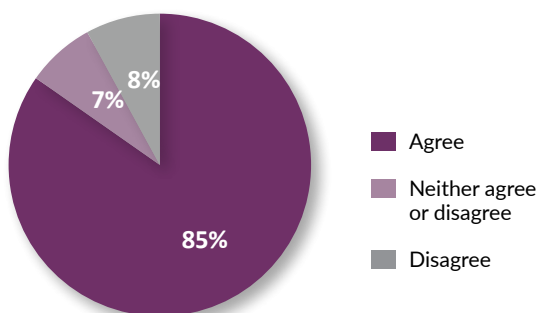
Cultural views/beliefs impact my position or views on voluntary assisted dying



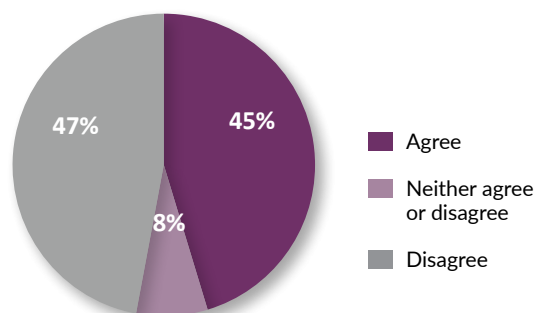
Religious views/beliefs impact my position or views on voluntary assisted dying



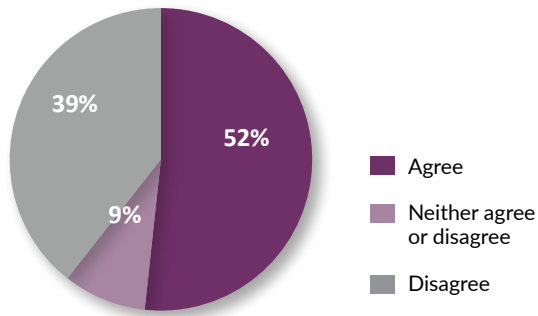
I am aware of the VAD legislation in other states and territories in Australia



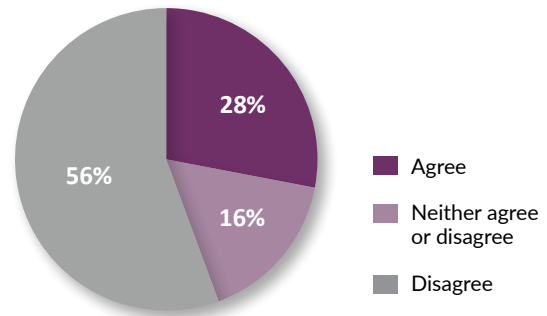
Someone should only be allowed to access VAD if their life expectancy is 6 months in most cases, 12 months for neurodegenerative diseases



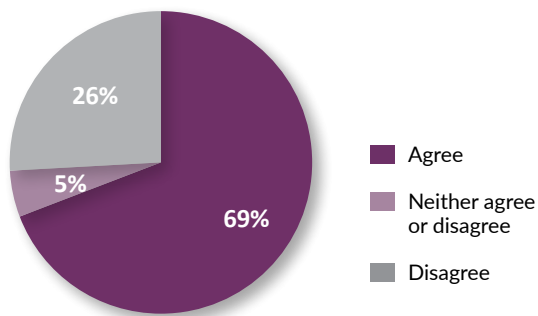
A person should have a terminal illness diagnosis to access voluntary assisted dying



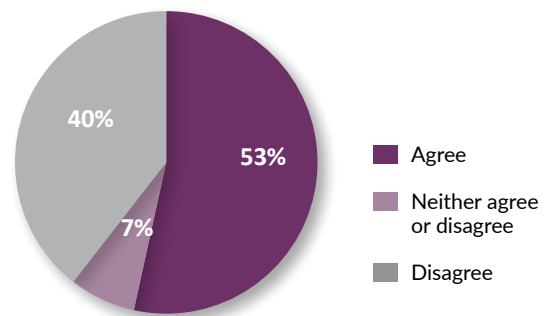
A person should be able to access VAD if they only have a mental health condition as the reason for their access



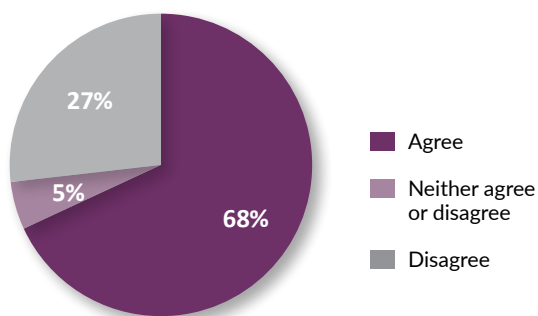
A person should be allowed to access VAD if they are experiencing intolerable suffering



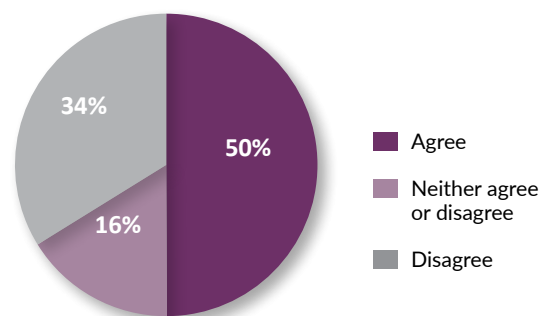
Someone should only be allowed to access VAD if, regardless of their life expectancy timeline, they are dying from a terminal and progressive illness



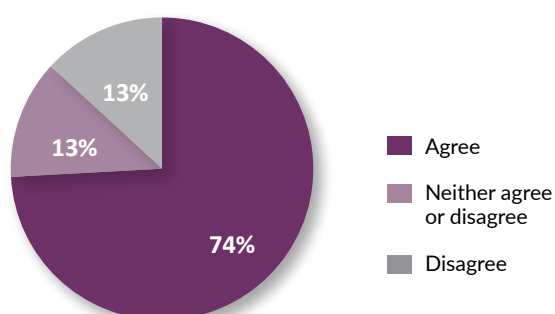
A person should be able to access VAD if they have a terminal illness diagnosis and a mental health condition



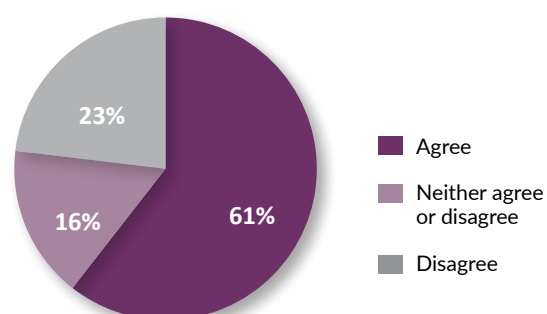
A person should be over 18 to access voluntary assisted dying



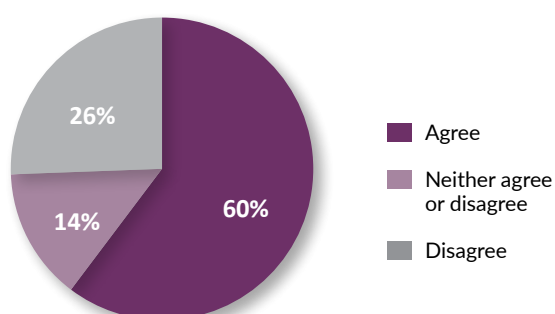
There should be an independent oversight body to review and approve compliance of VAD in the NT



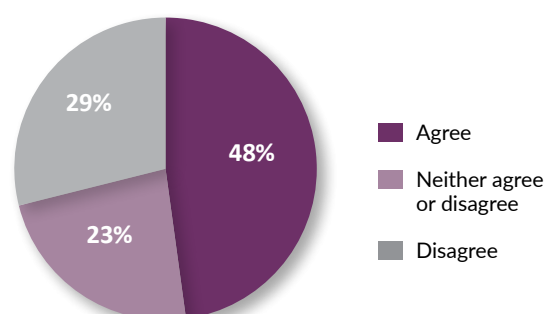
There should be specific offences, for health practitioners who fail to comply with the VAD process, including criminal offences and reporting to licensing authorities



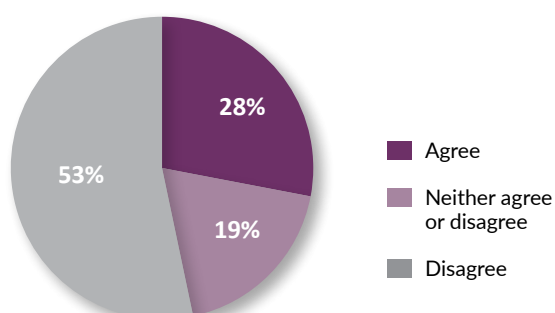
A person's terminal illness should be recorded as the cause and manner of death on their death certificate if they have accessed voluntary assisted dying



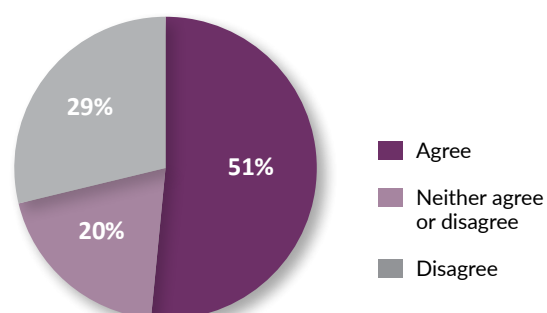
A person should be an Australian citizen or long-term resident of Australia to access voluntary assisted dying



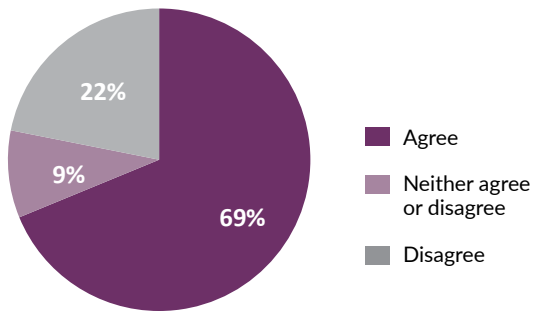
A person who is ordinarily a resident in the NT should only be able to access VAD in the NT



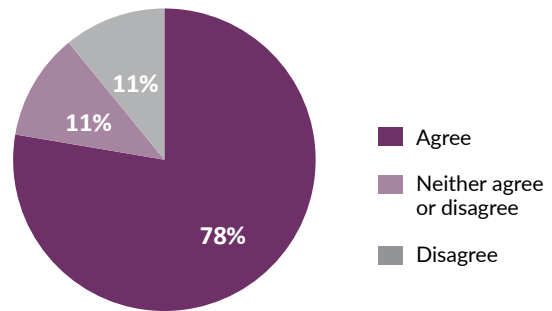
A person who is legally in the NT (with a work visa or similar), but not a citizen, should be able to access voluntary assisted dying



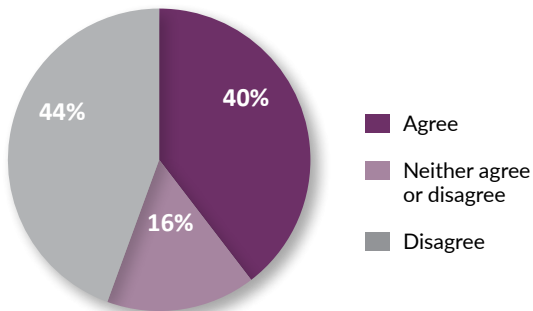
A person should be able to choose when they die



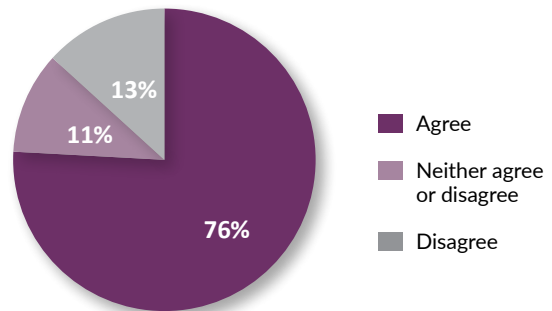
Medical professionals should be allowed to start a discussion about VAD with their patients if they also provide all other treatment and care options



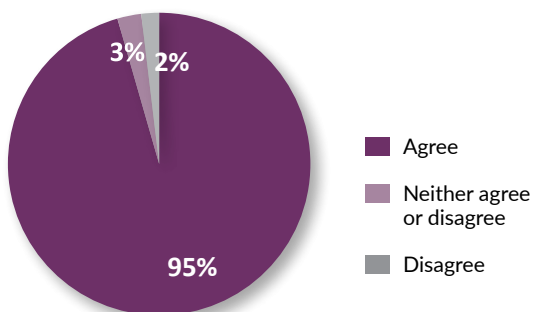
A person should be required to make multiple requests to access voluntary assisted dying



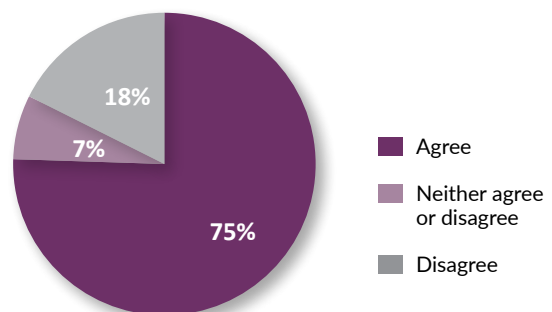
A person should be required to take time to reflect (or a 'cooling off' period) before they make their final request to access voluntary assisted dying



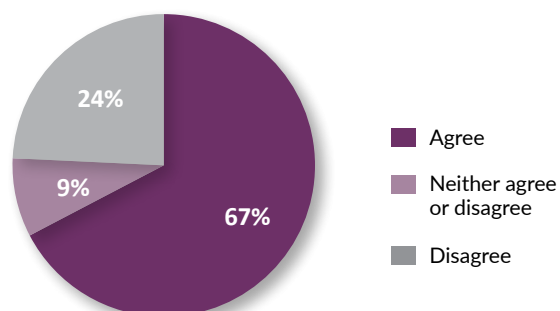
A person should be able to withdraw from the VAD process at any time that they choose



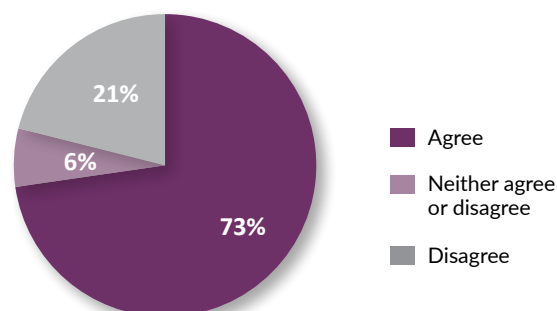
People should be able to access assessment for the VAD process in a hospital



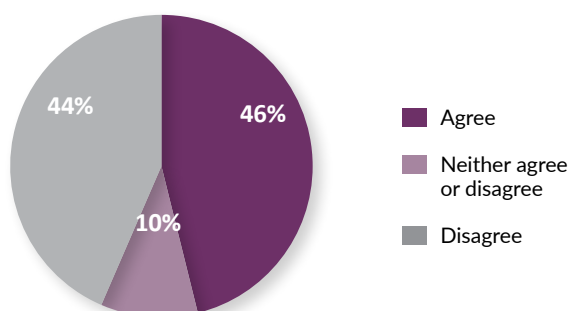
People should be able to access assessment for the VAD process at their local clinic



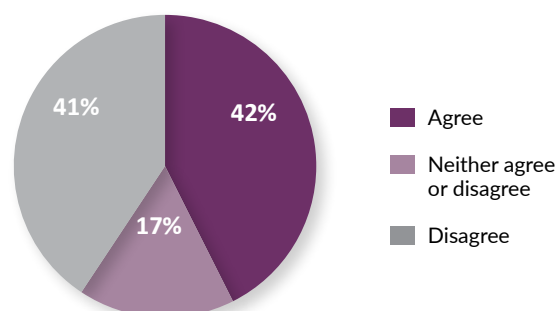
People should be able to access assessment for the VAD process at home



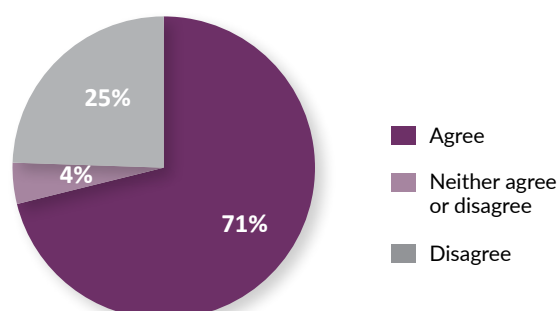
People should be allowed to use online carriage services (e.g. Telehealth) to undertake medical consultations to access voluntary assisted dying



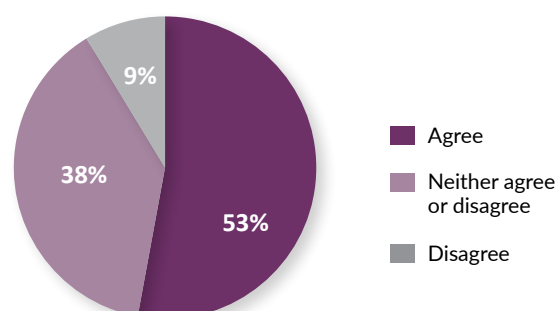
People should only be allowed to use online carriage services (e.g. Telehealth) to undertake medical consultations to access VAD if their initial assessment was face-to-face



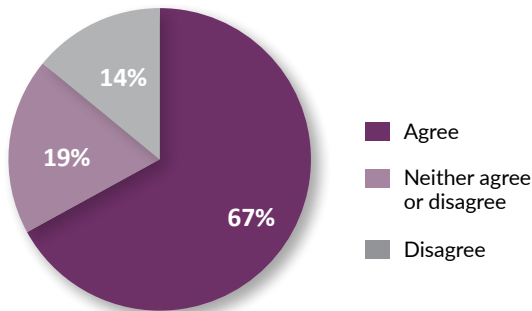
Someone should be able to say in their advanced care plan that they want to have the option for VAD in the future, even if they don't have the capacity to make that decision themselves.



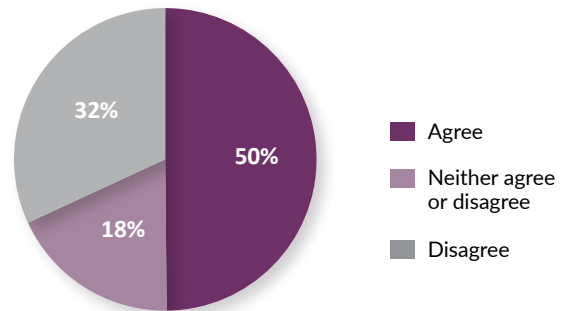
(If you agreed with the statement that a person should be required to make multiple requests to access voluntary assisted dying, how many requests should a person have to make?)



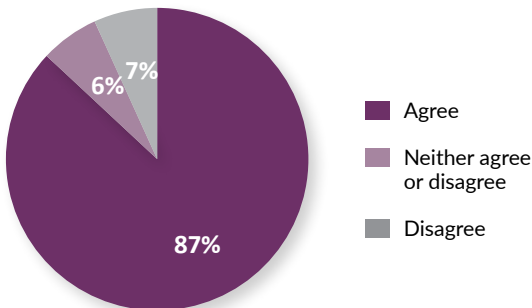
Administering of the VAD substance should be witnessed by another person



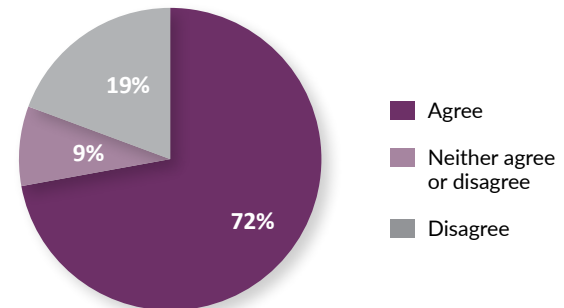
A person should be required to self-administer or have the VAD substance administered by a health professional within a set time period after the final request



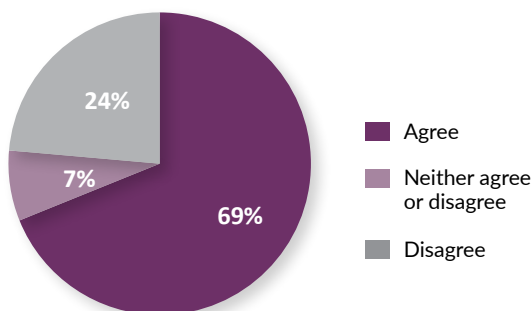
A person should be required to return the VAD substance if they choose not to use it



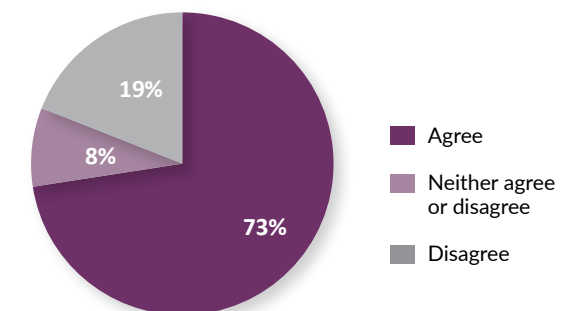
A person should be able to choose self-administration or administration by a health professional of the VAD substance



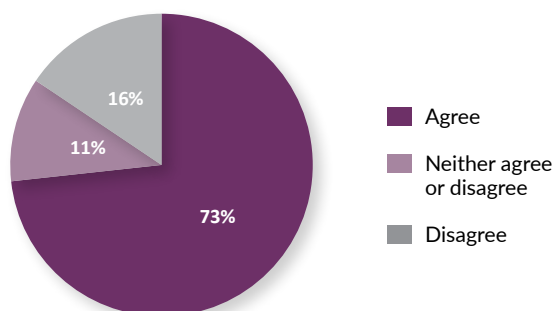
People should be allowed to self-administer the VAD substance in their home or place of residence



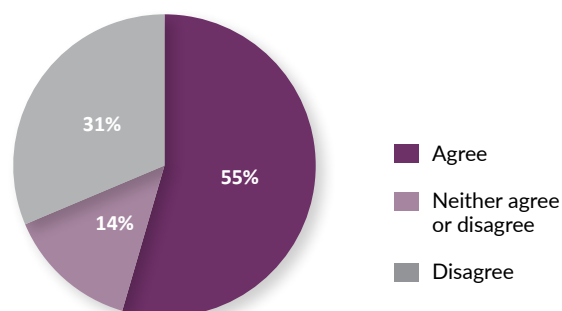
People should be allowed to self-administer or have the VAD substance administered in a hospital



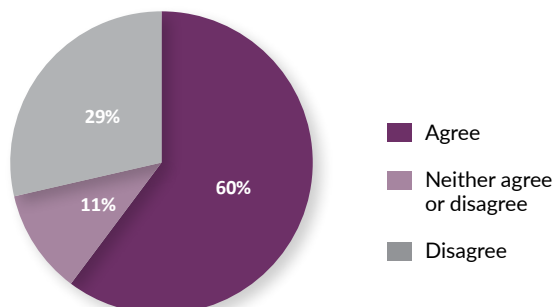
More than one medical professional should be required to assess a person who has requested to access voluntary assisted dying



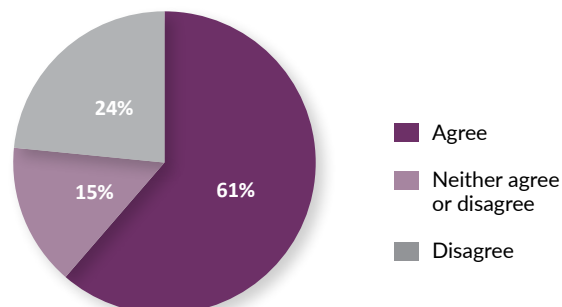
Only doctors should be able to assess if a person is allowed to access voluntary assisted dying



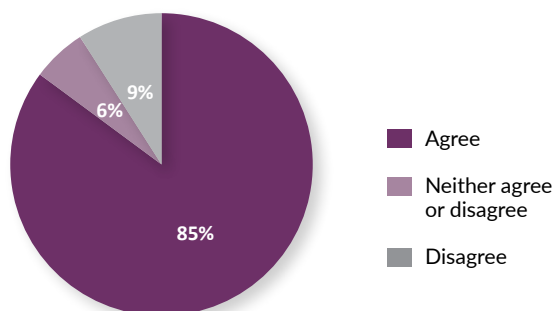
Doctors and nurse practitioners should be able to assess if a person is allowed to access voluntary assisted dying



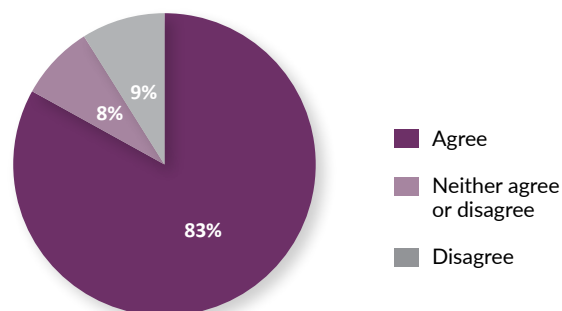
A mental health professional should be required to assess a person before they can access voluntary assisted dying



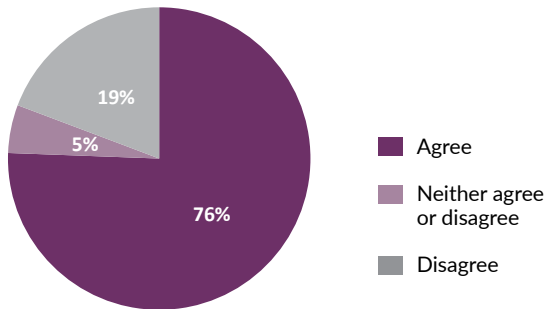
A medical professional should be able to conscientiously object (decline to be involved in the VAD process)



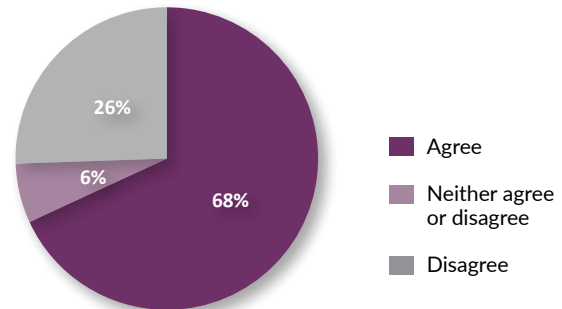
A medical professional should be required to immediately tell a person if they are a conscientious objector



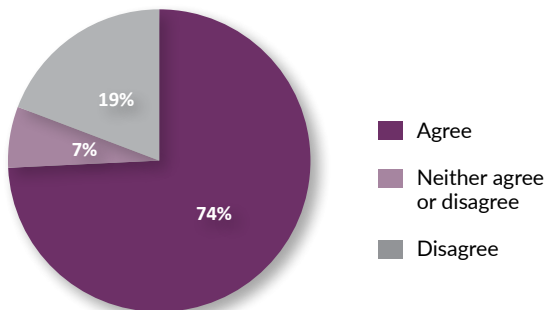
A medical professional that does not want to be involved in the VAD process should be required to refer a person to another medical professional or navigator service



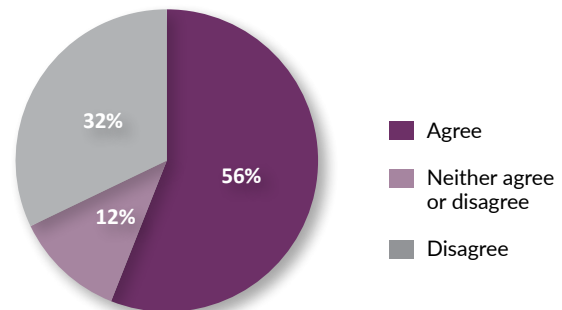
Medical professionals should be allowed to start a discussion about VAD with their patients if they also provide all other treatment and care options



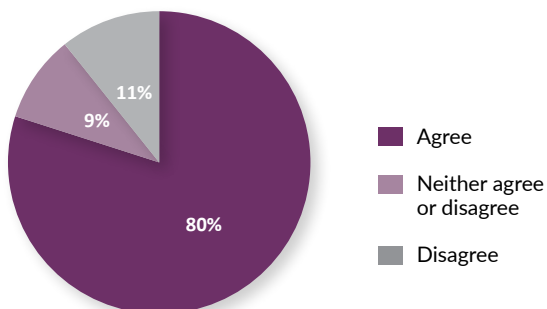
Doctors and nurse practitioners should be allowed to administer the VAD substance if they have done the appropriate training



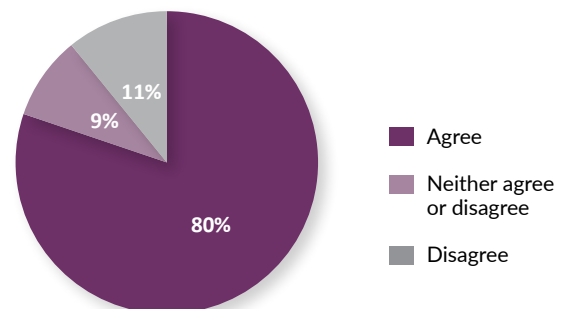
Health services should be allowed to choose to not facilitate VAD at its facilities (e.g. residential aged care facility, hospital, accommodation for people with a disability)



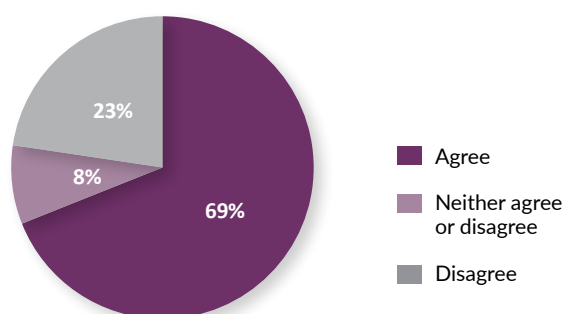
Health services should be required to make their position on VAD publicly available



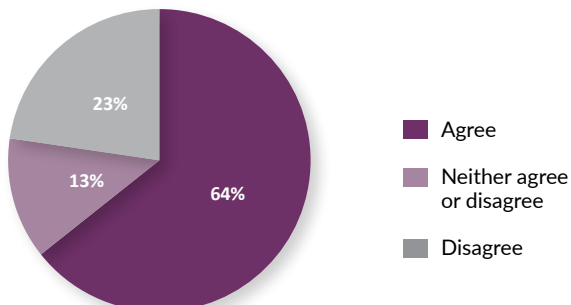
Medical professionals should be required to undertake specific training to assist with the VAD process



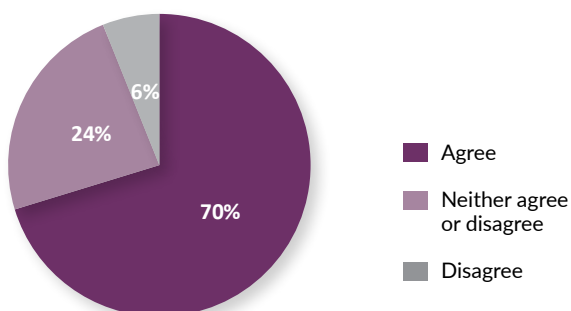
VAD training should be included in curriculums for all medical professionals



VAD training should be subsidised for medical professionals



(If you agreed with the statement that more than one medical professional should be required to assess a person who has requested to access voluntary assisted dying, how many medical professionals would be appropriate?)



APPENDIX 8

SUMMARY OF VOLUNTARY ASSISTED DYING PROCESS BY STATE

Victoria

1	First request is made to a registered medical practitioner, who makes a record and becomes the coordinating medical practitioner (CMP)
2	CMP makes the first assessment. If they are unable to determine capacity, they must refer to a medical practitioner with appropriate training and skills (e.g. psychiatrist).
3	Neurodegenerative conditions must be referred to a specialist in that disease area. That opinion is binding.
4	CMP must give the person information about treatment options (including risks). Person and Board are notified of the outcome of the first assessment.
5	Referral for consulting assessment; person advised within seven days of referral and must accept or reject. Cannot accept unless experienced in the condition likely to cause the person's death. Consulting assessment repeats process for first assessment (second opinion in case of refusal is available).
6	The written declaration requesting VAD once assessed by CMP and consulting medical practitioner is to be witnessed by someone over 18 and eligible
7	Final request for VAD, only if the written declaration is witnessed and certified. Must be made personally (verbally or by gestures). Must be at least nine days after the first request and at least one day after the second assessment. Exemption where death within nine days is likely.
8	A person must appoint a contact person responsible for the substance.
9	Final review by CMP for compliance and certification, submitted to the Board within seven days of completion.
10	VAD permit issued for self-administration or practitioner administration, including authority of contact person responsible for the substance. Permit is issued by Secretary of Department of Health and the Board is notified.
11	Administration request to be made by the person to the CMP (who must remain satisfied that all criteria is met) once all prior steps are completed. Request may be made verbally or by gesture, and must be in the presence of a witness. Administration occurs immediately after.

New South Wales

1	First request made during a medical consultation. Request may be verbal or not verbal (if not verbal, must be clear and unambiguous).
2	Medical practitioner may refuse or accept (unless not qualified) and must inform patient of decision, and notify the Board. First Request Form?? Medical practitioner becomes CMP.
3	CMP conducts first assessment. If unable to decide, must refer to another medical practitioner. Referral for other reasons including voluntariness, pressure or duress
4	If assessed as eligible, CMP must advise patient of mandatory list of matters and must fully explain a plan for VAD. CMP must be satisfied that the patient understands all information before determining eligibility. CMP must inform patient ASAP and notify the Board First Assessment Report Form (has a long list of inclusions).
5	Consulting assessment – similar procedure for refusal or acceptance. Medical practitioner must notify Board within 5 days Consultation referral form and becomes the Consulting Practitioner.
6	Patient makes written declaration requesting access to VAD Approved Form signed by patient, or if unable to sign, declaration must be witnessed by eligible witness. Interpreter must certify (if applicable).
7	Final request to CMP, must be clear and unambiguous, in person (if practicable), verbally, or another way. Cannot be made less than five days after declaration, unless death is imminent. CMP must review all forms and the patient's declaration, then complete the Final Review Form, copy to be sent to the Board.
8	Administration decision (self or practitioner administration). CMP must complete Administration Decision Form. Self-administration permits CMP to prescribe substance to patient if CMP has been given the Contact Person Appointment Form. Agent of patient can possess, prepare, and supply the substance. They can also give unused substance to an authorised disposer. They can be any adult and can include the CMP or CP.
9	CMP may apply to Board for a VAD substance authorisation for the patient Approved Form. Board must decide application, and must refuse application unless all forms are provided. Board must notify CMP within two business days.
10	CMP must provide information on substance before dispensing it to patient or contact person.
11	CMP prescribes substance and gives it to authorised supplier, who must authenticate and confirm identity of CMP and patient. Authorised supplier must give information to patient agent/contact, and complete Authorised Supply Form.

Queensland

First Request

- 1 A person makes first request to a medical practitioner.
Must be clear and unambiguous, and made by the person (not by anyone else on their behalf).
Made verbally or by any other means of communication (e.g. gestures).
- 2 If the medical practitioner is not eligible to be the co-ordinating practitioner, they must decline the request.
If they are eligible, they must give the patient approved information and decide whether to accept the request.
If they accept, they become the coordinating practitioner (CP).

First Assessment

- 3 CP must assess the person and determine whether they are eligible.
If CP is satisfied, must give patient information (10 matters from checklist).
Must complete First Assessment Record Form and give a copy to the
If CP unable to determine if eligibility, must refer for determination to a referee

Consulting Assessment

- 4 Same eligibility requirement for consulting assessor.
Must decline or accept referral, complete a record and notify the Board.
If they accept, they become the 'Consulting Practitioner.'
Same referral process as step 3 if they are unsure.
Must give patient same information as CP (10 matters), and inform CP of outcome. Complete Consulting Assessment Record Form and give a copy to the Board.
CP can get a second opinion if there is an adverse assessment by consulting practitioner.

Second Request

- 5 Made after completion of assessment and must be in writing, in the approved form and signed by the person or eligible substitute in the presence of two witnesses.
All witnesses must be eligible witnesses.
CP must make record and provide a copy of the form to the Board.

Final Request and Review

- 6 Person makes final request.
Must be clear and unambiguous (verbal or by gesture).
Cannot be made within nine days of first request unless death or loss of capacity likely to occur within nine days.
CP must record final request and notify the Board, then review all previous forms/requests and complete Final Review Form and give a copy to the person and the Board.



Queensland

Administration Decision

After completion of the final review form, person may decide whether to self-administer or practitioner administer.

7

Practitioner administration is only available if self-administration is advised as inappropriate.

Administration decision must be clear and unambiguous, and made personally.

If revoked CP must record in medical record, complete a Record of Revocation in approved form and give a copy to the Board.

Appointment of Contact Person

If an administration decision has been made, the person must appoint a contact person (using Contact Person Appointment Form).

8

Must be signed by person and contact person.

Must be given to CP and CP to pass on to Board.

CP cannot prescribe VAD substance until contact person form received.

Board informs contact person of requirements regarding substance and support services.

Contact person must inform CP if person dies other than from VAD.

Authorisation

9

If self-administration is to occur, the CP is authorised to prescribe a VAD substance. Must give written information (11 matters).

The authorised supplier is to possess, prepare and supply the substance to the person.

An administering practitioner is authorised to administer the VAD substance in the presence of an eligible witness.

Authentication

10

Authorised supplier of prescription VAD substance must authenticate the prescription and give listed information in writing (9 matters).

Must complete Authorised Supply Form and provide a copy to the Board.

South Australia

1	First Request Person makes first request to a medical practitioner. Must be clear and unambiguous, and made by the person.
2	Medical practitioner may accept or decline. If they accept, must record this in patient's record. Medical practitioner becomes co-ordinating medical practitioner (CMP).
3	First Assessment CMP must assess the person and determine if they are eligible. If CMP unable to determine if eligibility, must refer for determination to a referee. Referral must be to a specialist in the disease/condition that will cause death (mandatory requirement). This specialist must then provide a clinical report. CMP must provide listed information to the patient, must be satisfied of the requirements and then notify the person of the outcome of the assessment. Must complete the First Assessment Report Form and provide to the Board.
4	Consulting Assessment Practitioner must accept or decline, as per the CMP. If accepted, they become the consulting medical practitioner. Consulting medical practitioner must be satisfied the person meets the eligibility criteria. If they do meet it, they must inform the person of seven matters and notify them of the outcome of the assessment. If assess the person as ineligible, they may refer the person to another consulting medical practitioner.
5	Written Declaration Person makes written declaration requesting VAD. Declaration must be signed and witnessed by an eligible witness.
6	Final Request Person may make a final request personally to CMP once declaration has been made. Must be made at least nine days after the first request unless death/incapacity likely in less than 9 days but at least one day after consulting assessment is completed.
7	Appoint Contact Person After making final request, a person must appoint a contact who is over 18. Must complete Contact Person Appointment Form. Interpreters must certify.
8	Final Review CMP must review all previous assessments and forms, and complete Final Review Form and certify that the request and assessment process has been completed. Copy of the form must be given to the Board.



South Australia (Cont.)

Apply for VAD Permit

CMP applies for VAD permit from the Chief Executive.

Either self-administration permit (default) or practitioner administration permit.

9 Practitioner administration permit authorises practitioner to administer in the presence of a witness.

CEO must determine application within prescribed period and notify CMP and the Board.

Permit cancelled on destruction of unfilled prescription or on pharmacists giving the Board the Completed VAD Substance Disposal Form.

Prescribing VAD substance

The CMP must before prescribing, inform the person of the required matters (seven matters)

10 The pharmacist must inform the person to whom the substance is supplied of five matters.

Pharmacist must complete the VAD substance dispensing form and give to the Board.

If any of the substance is returned, pharmacists must dispose of substance and complete VAD substance disposal form and give to the Board.

Administration request

Person makes administration request to CMP. The request must be witnessed and the administration of the VAD substance must be witnessed.

11 Although unclear, appears that it must be the same witness.

Witness must certify the coordinating medical practitioner administration form completed by CMP.

CMP must give to the Board.

[A Request is not necessary for self-administration].



Western Australia

1	First Request Medical practitioner, must be clear As well as unambiguous. Provide a medical consultation made in person (if possible). Maybe verbal or by gesture.
2	Acceptance Medical Practitioner must accept or refuse. Must inform patient within two days and supply information approved by CEO. Must make a record in the patients' medical record and notify Board with first request form. Medical practitioner becomes Co-ordinating Practitioner (CP).
3	First Assessment CP must assess whether patient is eligible for VAD. If unsure of any criteria of disease, capacity, coercion, may make appropriate referral. If eligible, CP must provide patient with information about 10 matters. CP must then make assessment of whether patient is eligible. CP must notify patient and within two days first assessment report form must be given to Board. If eligible, patients is referred for consulting assessment.
4	Consulting Assessment If a patient is referred to a medical practitioner for consulting assessment, medical practitioner must accept or refuse referral. Must complete consultation referral form and give a copy to the board. If medical practitioner accepts referral, becomes the consulting practitioner. Consulting practitioner must assess whether patient is eligible; similar referral process applies as for CP.
5	Written Declaration Eligible person may make written declaration in approved form given to CP. Written declaration must signed by patient and eligible witness. CP must record giving of declaration in patients' medical record and must notify Board within two days.
6	Final Request and Final Review Patient makes final request must be clear and unambiguous, in person. May be oral or by gestures. Final request cannot be made within nine days of first request unless likely to die or lose capacity within nine days or at least one day after consulting assessment. CP to notify board of final request within two business days final request form. CP must review all previous documents and complete final review form.
7	Administration Decision Patient decides whether to self-administer or have administration by administering practitioner. If the patient revokes an administration decision the CP or AP must record the revocation on the patients' medical record and complete the revocation form and give a copy to the Board.

Western Australia (Cont.)

8	Self-Administration supply The CP is authorised to prescribe a VAD substance to the patient. The authorised supplier who is given the prescription is authorised to possess, prepare and supply the substance to the patient, contact person for patient or agent. Patient is authorised to self-Administer. Agent/contact person is authorised to supply (not administer). Practitioner Administration Supply CP is authorised to supply to either CP or AP. AP is Authorised to administer the VAD substance in the presence of a witness.
9	Contact Person A patient who chooses to self-administer must appoint a person as the contact person. This can be the CP or consulting practitioner. Must complete the contact person appointment form. Signed by patient and contact person.
10	Authentication Authorised Supplier of medication must authenticate prescription. Authorised supplier must give information to patient, contact person or agent. Authorised supplier must complete authorised supply form and notify the board. Authorised disposes to record and notify of disposal of unused substance by authorised disposal form. Administering practitioner may dispose of unused substance and complete practitioner disposal form.
11	Notification CP must complete the administration decision and prescription form and give a copy to the board (with the contact person appointment form for self-administration). AP must complete the practitioner administration form and provide to the Board. A witness to administration must not be an ineligible witness.



Tasmania

1	Person who indicates wish to access VAD to a GP must be given contact details of the Commission.
	First request
2	to a medical practitioner in person (not telehealth) or in writing (signed). Must be refused or accepted within 48 hours; notified within seven days.
	Acceptance of request makes medical
3	practitioner the primary medical practitioner; notifies person within seven days of acceptance; PMP may refer person for a medical examination; obtain medical records or any other relevant information;
4	Determination of first request in writing; notified to the Commission.
	Second request to PMP not less than 48 hours after first request (unless death within 7 days or decision making capacity lost within 48 hours likely)
5	In writing signed and witnessed by two witnesses (one independent) Second request decision must be in writing and contain relevant information about eligibility.
6	Referral for second opinion by another medical practitioner (CMP) – maximum of two referrals possible. CMP follows same process as PMP; notifies Commission.
7	Determination of eligibility made and advised to PMP.
	Final request to PMP to assess eligibility.
8	Must not be within 48 hours of second request unless death within seven days likely. Must be in writing and signed; PMP gives a copy to the Commission.
	PMP may refer for another examination etc.
9	Final determination in writing; notified to commission PMP or other practitioner becomes Administering Health Practitioner (AHP).
	PMP requests Commission to administer VAD substance authorisation.
10	Commission issues VAD substance authorisation to PMP. PMP issues a VAD substance prescription. Pharmacists supplies substance to PMP who in turn supplies it to AHP (if not the PMP).
	Final permission obtained from person by AHP after determining capacity of person within 48 hours before permission and giving mandated advice.
11	AHP may refer for examination etc. Final permission is in writing and signed. Substance administered by AHP or Private self-administration request and certificate (must nominate a contact person).



APPENDIX 9

Cultural issues relevant to VAD in the NT

There are a number of Aboriginal and Torres Strait Islander cultural issues which the Panel acknowledges are important. The requirement to provide an accessible model of VAD should be considered through this lens, particularly the concerns for any Aboriginal and Torres Strait Islander people who may seek to use these services. The concerns also highlighted broader potential impacts on Aboriginal and Torres Strait Islander communities that could flow from the development of VAD services in the Northern Territory.

This appendix provides a brief discussion of the key cultural issues for Aboriginal and Torres Strait Islander that were identified, and some of their implications for establishing and implementing a model of VAD in the NT.

Intergenerational trauma and the need for trauma-aware approaches to care¹

The Panel has been made aware of the health impacts of ongoing disempowerment. The high burden of disease and premature mortality in the Aboriginal and Torres Strait Islander community has to be understood in that context.

- o There continues to be an underlying level of mistrust, fear and suspicion of health services and of authority amongst some Aboriginal and Torres Strait Islander people.
- o Cumulative bereavements in Aboriginal or Torres Strait Islander families are a source of trauma and are likely to affect people's response to Voluntary Assisted Dying.
- o It will be important that trauma-informed practice² is incorporated into VAD processes and communications at all levels, whenever engaging with patients, families and communities.

Individual versus kinship decision-making, and family involvement in care

Whilst some Aboriginal and Torres Strait Islander people make their health decisions independently, for others it is their choice (and it is culturally appropriate) for their family to make decisions for, or with them.

- o Recognition of culturally safe practices of kinship decision-making should be acknowledged within NT VAD legislation. In effect, this will require that concerns about confidentiality or coercion are balanced against the person's request for family involvement. This balance should be able to be set by the person seeking VAD.
- o It must be recognised that the role of a "contact person," which is identified in other jurisdictions³ as a support for a person who wishes to self-administer VAD, and who has specific legal responsibilities for the VAD substance, may present extremely significant cultural challenges within some families or communities, where that person could be believed to be responsible for the VAD recipient's death.
- o It will be important to be able to provide male or female-specific health care arrangements as culturally required.

Language, and the role of interpreters and cultural brokers

The Panel is aware that cross-cultural communication requires not just language interpretation, but also an element of cultural brokerage to ensure that that communication is appropriate and safe.

- o VAD assessment and informed consent needs to occur in the person's preferred language, and usually this will be their first language.
- o There are specific potential challenges relating to cross-cultural communication⁴. These issues may become particularly significant when assessing whether decision-making is fully informed and voluntary, and if it represents a sustained request.

1 McCallum D (2022) Law, justice, and Indigenous intergenerational trauma—a genealogy. *International Journal for Crime, Justice and Social Democracy* 11(3): 165-177. <https://doi.org/10.5204/ijcjsd.2121>;

Darwin, L., Vervoort, S., Vollert, E., Blustein, S. (2023). *Intergenerational trauma and mental health*. Canberra: Australian Institute of Health and Welfare;

Trauma - Healing - Australian Indigenous HealthInfoNet (ecu.edu.au) Accessed March 26, 2024

2 Trauma informed practice | Mental Health Australia (mhaustralia.org)

3 For instance: Being a contact person—VAD (health.qld.gov.au)



- o Some very small language and kinship groups may have limited access to trained interpreters, and if they do there is a high likelihood that the interpreter will be related to the person seeking VAD. It will be important that interpreters and cultural brokers are able to choose not to be involved in VAD discussions and assessments, either because of their own beliefs, or due to their specific relationship with the patient or their family.
- o The Panel is aware that there are culturally constrained ways of communicating about prognosis and death, which vary between different cultural groups⁵, and that clinicians who discuss VAD with Aboriginal patients and families will require cultural competence in this area, and the support of cultural brokers.
- o NT-wide communications about the availability of VAD and promotion of the service will need to be delivered in a way that is least likely to be misunderstood.

Varying cultural understandings of illness and death, its causes, and associated practices

The Panel been involved in a number of discussions about the cultural aspects of terminal illness, death and dying in Aboriginal and Torres Strait Islander communities.

- o It will be important to recognise that there can sometimes be concerns about blame and determining responsibility for a death within families and communities, and sometimes blame may also be attributed to health care providers, which could have wider impacts on health services.
- o For some Aboriginal and Torres Strait Islander people, acceptance of the biomedical “illness story” is limited, and cultural understandings of disease and the causation of death may be very different from the medical perspective. Prognostic information that has an element of uncertainty may be particularly difficult to discuss.
- o Access to cultural supports such as traditional healers will be important for some people, and it is likely that these senior cultural practitioners will sometimes contribute to individuals’ decision-making.
- o It will be important to consider and try to facilitate decisions about the preferred place of death, in particular if the person wants to return to country to finish up. However, communities’ specific practices around death and dying may affect the provision of VAD, and also the preferred place of death.

The impact of remoteness, and the infrastructure present in remote communities

The majority of people living in very remote communities in the NT are Aboriginal or Torres Strait Islander people, and they therefore face additional challenges in accessing all health care services, including any provision of VAD in future.

- o Clinics, which provide the primary health care services to remote communities, are often community-controlled and are a critical part of the infrastructure for these communities. They have a high degree of accountability within the community, and staff are very identifiable. Provision of VAD in clinics, or by clinic staff, may be culturally challenging. Use of clinic facilities for assessments may not be appropriate or private. Considerations around providing, storing and managing medications for VAD present real concerns for many remote clinics.
- o The logistics of accessing VAD for people in remote communities, should it be requested, may require a significant amount of travel by either the applicant or the VAD providers, and to ensure equitable access to the service this must be adequately resourced.

4 Important, common communication challenges have been well-described in the legal setting.. Commission Submission - ON COMMON DIFFICULTIES FACING 7ABORIGINAL WITNESSES | Australian Human Rights Commission Similar issues have been identified in the health care setting.

5 PEPA_CulturalConsiderationsFlipbook_Web.pdf (pepaeducation.com) (Accessed 3/4/2024)

APPENDIX 10

Dementia and VAD

Dementia was an issue which was repeatedly raised in a number of written submissions, both for and against VAD generally and in respect of people with dementia specifically.

"[6] my aunt and godmother developed dementia soon after her retirement from work in her early 60s. She quickly developed to having no cognitive function but remained alive for another 5 years basically as a 'vegetable' or a 'baby who never grows up'. This was not a life for her."

- personal account

"My ex-father-in-law is 95 and has dementia and has had a stroke. He has no cognitive ability. He would not seek that life. He was playing golf to his late 80s and was driving his car until 2 years ago. He is sedated and is slowly starving to death."

- personal account

Dying with Dignity Victoria (DWDV) sent a written submission (#69) to the Panel, in which they said:

"... while DWDV acknowledges the challenges associated with making VAD available to people with dementia, we feel compelled to raise this issue on behalf of our members and supporters, who consistently highlighted it as their overwhelming concern. A survey of members and non-members conducted by DWDV in late 2022 indicated considerable levels of distress and frustration that VAD is unavailable to people dementia. This appears consistent with broader community concerns expressed in recent media discussions of the topic."

Dementia Australia, the peak dementia advocacy organisation in Australia, sent a written submission (#30) to the Panel. It noted:

"It is often assumed that people with dementia, and associated cognitive decline, lack the ability to make decisions. A person with dementia will experience cognitive decline but this depends on the type of dementia they develop as well as a range of other variables which will be different for every individual. Some people living with dementia will maintain a degree of cognitive ability for a significant time post diagnosis while others will experience a more rapid decline. Given dementia is a progressive condition, there is support among people impacted by the disease for the view that individuals with dementia should be able to make the decision to access VAD while they still have the ability to do so. Equally, people living with dementia, their families and carers have also expressed concern about the potential for people with dementia who did not have the ability to make an informed decision about VAD to be vulnerable to influence or manipulation."

There are several aspects to making VAD available to persons diagnosed with dementia, each of which has its own range of issues or challenges.

Firstly, consideration may be given to enabling a person diagnosed with dementia to be able to access VAD at a time prior to the dementia taking away the person's decision-making capacity. The usual progression of dementia is that the loss of decision-making capacity occurs slowly and sporadically. In that way, a person who has received a diagnosis of dementia may continue to lead a relatively normal life for a long period of time after initial diagnosis. In Australia, all jurisdictions other than the ACT have limited access to VAD to a person who is within six or 12 months of death and who continues to have decision-making capacity. Those provisions all but rule out the ability for a person diagnosed with dementia to access VAD at a time when they still have decision-making capacity. For people in that situation, invariably the prognosis for natural death would be unknown or, at the very least, well in excess of 12 months.

In order for a person diagnosed with dementia to be able to access VAD prior to loss of decision-making capacity, in all but a very few cases the person would have to choose to end their life through VAD at a time long before the last six or 12 months of life. It would be necessary to remove the time limitation of a prognosis for natural death in the case of someone diagnosed with dementia. Without such a limitation, a person diagnosed with dementia but still with sufficient cognitive function that they maintain decision-making capacity would be able to access voluntary assisted dying, but their death would occur long before – in many cases years before – their expected natural death as a result of dementia.

The Panel had direct engagement with a couple living with dementia. They preferred to be able to complete an advanced directive which was tailored to specific indicia of independence and quality of life such as "lingering in a vegetative state, unable to communicate verbally nor self-care". However, one of them also said that if he had to make a decision on the timing of his death at a time when he still had capacity, he would be comfortable with that.



The second way in which VAD could be made available to persons diagnosed with dementia is through the use of an advanced directive. Proponents of this alternative point to the existing arrangements under which a person can make an advanced directive regarding health treatment. For example a directive to do no resuscitate. They argue it should be possible to make a precise advanced directive identifying a point at which they are to be administered a substance to assist them to die.

"There is strong support in the community for a person to be able to request VAD in advance care planning documents, so that assisted dying could take place after the person has lost capacity. Submissions to all state VAD enquiries advocated this be provided for, however no state has accepted the challenge. Our society has long accepted that doctors, in consultation with family members, can lawfully remove life support when no hope of recovery exists, without the patient's consent. One can also give an enduring power of attorney in advance care planning documents to make life critical decisions in the event competence is lost. It is time for legislators to embrace the issue and devise an acceptable regime." - NT Voluntary Euthanasia Society, Submission 17

A number of people provided examples of the detailed instructions that could be included in an advance directive to enable VAD in cases of dementia or other loss of decision making capacity.

The End of Life Choice Society of New Zealand provided a written submission which referred to a form of advanced directive called an "Advanced Assisted Dying Request". The form was developed by EOLCS NZ as part of its advocacy for inclusion of advanced directives for dementia sufferers in New Zealand legislation. The form proposed that a person could nominate to access assisted dying when four or more of a number of nominated conditions were met including:

- I am no longer able to consistently recognise my closest family/friends, namely:
(name those who matter most)
- I become bowel and/or bladder incontinent
- I cannot maintain personal physical cleanliness on my own
- I am unable to dress myself without assistance
- I am unable to feed myself and require spoon feeding or artificial feeding
- I require permanent use of a wheelchair and my carers fear for my safety if I stand up
- I am unable to express my emotions verbally in a way my loved ones/carers can understand
- I become angry, aggressive and/or fearful for no logical reason
- I behave in embarrassing or degrading ways alien to my competent personality such as shouting, threatening, or exhibiting other unacceptable behaviours.

Advance directives are able to be used and acted upon under VAD legislation in Belgium and the Netherlands. Canada has proposed an amendment to its VAD law to enable use of advance directives in the case of loss of capacity (most commonly due to dementia).

In Canada, the Medical Assistance in Dying (MAiD) Act already contains two provisions which are at the very least consistent with the idea an advance form of consent could allow for VAD to be accessed by a person after they have lost capacity.

Opponents of making VAD available to people who have lost capacity have identified a number of issues in allowing such a provision. One submission from a Queensland medical practitioner reads:

"What happens if a patient with dementia, who has signed an advanced health directive for euthanasia at some later stage has, in the clarity of dementia, a mind change, but relatives have decided that a life has been lived and it is time for death? You need to read the accounts of the obscene struggles and assaults when this has happened in both Belgium and the Netherlands." - Submission 28

Numerous submissions referred the Panel to a case in the Netherlands in which a doctor was acquitted of a breach of euthanasia laws in circumstances where a patient with Alzheimer's who had signed an advanced directive appeared to struggle and resist the administration of a substance to cause her death.

People with a prognosis that includes future loss of capacity anticipate vulnerability due to factors over which they do not have direct control, including societal stigma, caregiver stress, and availability of adequate home and residential care.

In 2021 a Canadian study of attitudes to advance requests for assisted dying amongst clinicians found a slight majority in favour of a patient's right to seek assisted dying by an advanced directive but many were concerned about negative impacts and patient safety. Some clinicians identified the benefit of avoiding anticipatory anxiety about the potential progression of dementia as a reason for allowing an advanced directive. Another benefit was that it would reduce the prospect of a person seeking an earlier death through assisted dying before reaching the advanced stages of the disease. Barriers to an advance

request were identified as including difficulty with anticipating the interests or wishes of a person at an indefinite time in the future; navigating disagreement between family and/or medical providers; potential for abuse or secondary gain; and determining the appropriate time to act on an advance request.

A 2021 article examined the Dutch model of assisted dying in cases of dementia which uses a diagnostic assessment of early vs late disease stage to determine if a person has capacity to make a request or an advanced directive. The article identified empirical evidence suggesting patients requesting assisted dying once diagnosed with dementia may be incorrectly assessed as having competence and the directive accepted and acted upon. The article stated:

"The stage-based distinction risks disregarding the complex reality of the substantial portion of patients who are at the so-called margins of competence, that is, patients whose level of competence is unclear. These patients may, for example, have a retained ability to communicate, but without meeting the bar for competence. In other words, 'the various significant capacities can come apart' in some cases, complicating competence assessments (10). The difficulty is that these persons, while lacking competence according to the standard definition, 'are not yet at the point where their advance directive have the greatest authority' (10). This raises important questions about how they should be assessed in the context of PAD. The current Dutch practice considers these cases under the umbrella of early stage and competent, potentially overlooking important policy discussions about how these persons should be evaluated."

A December 2021 review of literature regarding physician assisted suicide (PAS) in dementia identified a number of potential dangers associated with assisted dying in dementia cases, including economic factors, caregiver burdens and risk to further research into behavioural and psychological symptoms of dementia. The review observed:

"[E]ven in countries where PAS is legal for advanced dementia, there is significant ambivalence among both physicians and caregivers. For example, in a survey of Dutch physicians, 53% reported a significant emotional burden when faced with dementia related PAS requests; 47% had difficulty in evaluating the competency of the patient with reference to informed consent; and 43% reported feeling pressurized by caregivers into approving the request. ... This could lead to consent or approval being given under duress, and thus being of limited validity. Second, though the 'advanced' or 'severe' nature of dementia may be evident in certain cases, there are others where it may be difficult to distinguish between 'early' and 'late' or 'moderate' and 'severe' cases (Nicolini, 2021). Third, there is evidence that the availability of PAS may compromise the general standard of medical care offered to such patients (Mathews et al., 2021). Fourth, it is also possible that patients with advanced dementia may be partially or wholly unaware of 'suffering' as we understand it, and that attempts to frame the debate in these terms may reflect the projection of caregivers' or physicians' opinions rather than the patient's actual situation."

In an opinion piece in the Sydney Morning Herald in July 2023, Emeritus Professor David Ames, an old-age psychiatrist argued against advanced directives for assisted dying in dementia. He said:

"Most people with dementia do not 'suffer', as they have limited awareness of their incapacity and functional decline; most seem content. Family members can be distressed on their behalf. But should we allow an assisted death to spare the suffering of relatives or to prevent notional future individual suffering that might never occur? While VAD might seem a liberating option for some, it could also become a duty or obligation to others. Assisted dying is a quick, cheap option for families and governments. Currently, those with dementia have a legitimate expectation of care, but if assisted dying is available, they will have to choose between care and death. Elder abuse (financial, physical, psychological and neglect) is widespread, with one in five aged people affected. This is often perpetrated by close family members. Inheritance impatience is also well recognised. The availability of VAD can be a disincentive for governments to provide better aged care options and limit research efforts as well."

In an article published in the Medical Journal of Australia the authors (who include one of the members of this expert panel) considered whether advance directives for people suffering dementia (or other progressive cognitive impairments) should be included in VAD laws in Australia. The authors concluded:

"In spite of the apparently straightforward nature of the idea, the extension of VAD to persons with dementia raises serious philosophical, ethical and social questions that challenge the way VAD is currently understood, enacted and applied.¹

Irrespective of whether such a national consensus can be identified, it seems most jurisdictions which have implemented VAD legislation after Victoria have been reluctant to diverge significantly from the precedent which that jurisdiction established. This may be for a range of reasons including to diffuse opposition to VAD by aligning with laws which have already successfully passed through Parliament and have been 'socialised' through a half decade or so of implementation. There is evidence initial assessments of VAD schemes for each of the Australian jurisdictions initially favour a more liberal scope of operation but restrictions have emerged in the form of compromise to ensure passage of legislation.

1 Medical Journal of Australia, Vol 220, Issue 9, May 2024, pp452-454

Notes

Handwriting practice lines consisting of 20 sets of three horizontal dotted lines.



