



Department of
Health

Statutory Review – *Voluntary Assisted Dying Act 2019*

Final Report 2024

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1. Introduction

The *Voluntary Assisted Dying Act 2019* (the Act) provides for and regulates access to voluntary assisted dying in Western Australia. The substantive parts of the Act commenced on 1 July 2021.

In accordance with section 164 of the Act, the Minister for Health appointed the Voluntary Assisted Dying Act Review Panel (the Panel) to review the operation and effectiveness of the Act. The Panel conducted this statutory review on behalf of the Minister for Health supported by the Department of Health.

Details about the panel members who oversaw this inaugural review are in Appendix A.

The Terms of Reference for the Review of the Act (the Review) are framed in terms of section 164 of the Act, with the Panel being directed to report on:

- the effectiveness and operation of the Act, as passed by the Parliament in 2019, in providing for and regulating access to voluntary assisted dying
- the extent to which current processes provided under the Act are operating to support persons eligible for voluntary assisted dying in Western Australia.

The scope of the review did not include whether voluntary assisted dying should be precluded or whether eligibility criteria for patients or practitioners involved in the voluntary assisted dying process should be broadened. These two issues were exhaustively discussed during the inquiries carried out by the Joint Select Committee on End of Life Choices and the Ministerial Expert Panel on Voluntary Assisted Dying. These issues were then debated in Parliament and the decisions of Parliament made clear in the terms of the Act. In the Panel's view, this approach adhered to the direction in the Terms of Reference to report on the operation and effectiveness of the Act as passed by Parliament in 2019.

This review was underpinned by an extensive stakeholder engagement process, the details of which are contained in Appendix B and consultation questions in Appendix C.

The Panel extends thanks and appreciation to all individuals and organisations who, by participating in the statutory review process, helped to generate the substantial amount of evidence that was considered as part of the Review.

2. Review of Act

The Panel has concluded that the Act is operating effectively in providing and regulating access to voluntary assisted dying for eligible people. The Act, as passed by Parliament in 2019, does not require legislative amendment. Processes provided under the Act are generally operating well in supporting all those involved in providing and accessing voluntary assisted dying.

However, the Panel has made recommendations about improving policy and operational processes as well as education, training and information materials to increase compliance with the Act, and improve access and support for eligible people and voluntary assisted dying providers.

2.1 Awareness of voluntary assisted dying

Evidence revealed that awareness of voluntary assisted dying is not consistently high across the State. Some stakeholders associated variable levels of access to voluntary assisted dying with a lack of awareness of the Act.

The Panel agreed with stakeholders that there is a need to scale up initiatives to help inform public awareness. The evidence also emphasised the need to ensure health professionals clearly understand end of life choices, including voluntary assisted dying. This is consistent with the Access Standard which facilitates access to information about voluntary assisted dying (as set out under section 156 of the Act).

Recommendation 1: That the Department of Health develop and implement a targeted strategy to improve community and health professionals' knowledge and awareness of voluntary assisted dying, the provisions of the Act and other end of life choices.

2.2 Understanding the first request

The Panel found that while other processes under the Act are operating as intended, in some circumstances the statutory obligations relating to the first request are not being consistently upheld. Stakeholders reported there is confusion among health practitioners, who wrongly believe that initiating discussions about voluntary assisted dying is prohibited under the Act. Medical practitioners and nurse practitioners can raise the topic of voluntary assisted dying, provided that they also discuss other end of life options. The Panel has been made aware of some misunderstanding among patients about what constitutes a first request, leading to delays in commencing a patient's assessment process for voluntary assisted dying, and subsequent access for eligible patients.

Recommendation 2: That the Department of Health reviews patient and health practitioner policies, education and training materials relating to the first request and the approved information (referred to in section 20(4)(b) of the Act) to ensure that understanding of how to make and respond to both voluntary assisted dying queries and first requests is maximised. This includes the obligations on all medical practitioners, including those with a conscientious objection who receive a first request, to comply with section 20 of the Act.

2.3 Conscientious objection

The Panel received evidence that the policies and practices adopted by some health professionals and institutions holding a conscientious objection to voluntary assisted dying are undermining the current processes provided under the Act. In the Panel's view, this has resulted in people eligible for voluntary assisted dying not receiving adequate support.

In the case of a voluntary assisted dying patient, as with all patients, registered health practitioners are bound by professional ethics and codes of conduct to ensure the safe and full transfer of patient care. Part of these obligations include medical records. If this is not occurring, the practitioner may be reported to the Health and Disability Services Complaints Office (HaDSCO) or the Australian Health Practitioner Regulation Agency (Ahpra). This is contemplated under the Act and the Australian Medical Association (AMA) Code of Ethics.

Recommendation 3: That the Department of Health:

- a) works with health, aged care and other providers to clarify and strengthen the processes pertaining to the provision of access to voluntary assisted dying. This may be achieved by several mechanisms, including:
 - amending the Department of Health Managing Voluntary Assisted Dying Policy for government institutions
 - working with non-government institutions to minimise the potential harm caused by institutional conscientious objection.
- b) as a matter of priority, undertake work with medical practitioners and associated professional bodies to review procedures relating to the provision of relevant clinical information when requested, with patient consent, by voluntary assisted dying practitioners.
- c) ensures that voluntary assisted dying information, education and guidelines for medical practitioners specifically include a reference to the timely transfer of clinical information.

2.4 Regional access

The Panel noted that there is strong support among stakeholders to uphold the principle of enabling equity of access to voluntary assisted dying for regional residents in line with section 4(1)(i) of the Act (see Appendix D for a list of principles of the Act). Many stakeholders reported that regional patients face significant challenges like traveling long distances to attend medical appointments associated with voluntary assisted dying. Other issues noted included higher costs, longer delays and greater difficulty in finding a coordinating practitioner.

The Panel found regional access to voluntary assisted dying would improve if current Commonwealth restrictions on the use of carriage services under the Criminal Code Act 1995 (Cth) were resolved (see 2.5). It is also clear that adequate practitioner resourcing and remuneration needs to be maintained to ensure that service provision for patients living in regional areas is preserved (see 2.6 and 2.7). The Panel noted that the Voluntary Assisted Dying Board monitors and reports on 'the extent to which regional residents had access to voluntary assisted dying' as per section 155(2)(g) of the Act, and '...having regard to the access standard under section 156.'

Recommendation 4: That the Department of Health ensures access to voluntary assisted dying for patients residing in regional areas is optimised through the Regional Access Support Scheme.

2.5 Criminal Code Act 1995 (Cth)

The Panel noted the ongoing challenges for patients accessing voluntary assisted dying services due to provisions contained within the Criminal Code (Cth). Under the Criminal Code, communications around some aspects of the voluntary assisted dying process, carried out through use of a carriage service, could constitute a criminal offence. While these restrictions affect everyone unable to attend face-to-face medical appointments, the burden on regional and outer metropolitan patients is disproportionately greater. The consultation showed strong support for revising the Criminal Code (Cth) to enable telehealth consultations and the use of electronic prescribing services in the voluntary assisted dying process. Importantly, as well as facilitating access to health practitioners, stakeholders also noted that amending the Criminal Code (Cth) would improve access to interpreters.

Recommendation 5: That the State Government continue to advocate for the Australian Government to amend the *Criminal Code Act 1995* (Cth) to improve equity of access to voluntary assisted dying.

2.6 Workforce resourcing

The Panel received evidence expressing strong praise for the voluntary assisted dying workforce. Many stakeholders highly valued the voluntary assisted dying practitioners, the Statewide Care Navigator Service (SWCNS), the Statewide Pharmacy Service (SWPS), interpreters and voluntary assisted dying coordinators within each of the health service providers. In the submissions received, the voluntary assisted dying workforce were broadly described as caring, considerate, respectful, diligent, empathetic and professional.

It is notable that the demands for voluntary assisted dying and the proportion of patients selecting practitioner administration have been higher than expected during the first 2 years of the service. This has led to workforce challenges, exacerbated by the constraints imposed by the Criminal Code (Cth) (see 2.5), and lack of remuneration under the Medicare Benefits Schedule (see 2.7). These challenges have been further compounded by the need for voluntary assisted dying practitioners, and particularly the SWCNS, to undertake a broader role in the ongoing care of patients and their families than initially anticipated to address the greater than expected demand.

A resolution of these issues alongside ongoing monitoring of service demand will ensure services are sufficiently resourced to respond to patient needs and support the sustainability of the workforce. The Panel also noted stakeholders raised resourcing issues in relation to services like grief and bereavement support, and participation in the Community of Practice, neither of which is mandated under the Act.

Recommendation 6: That the Department of Health:

- a) continues to monitor and evaluate the voluntary assisted dying workforce including the Statewide Care Navigator Service and the Statewide Pharmacy Service.
- b) ensures that health service providers are meeting their responsibilities as outlined in the Managing Voluntary Assisted Dying Policy including appropriately resourcing the voluntary assisted dying workforce.

2.7 Workforce remuneration

The Panel noted that there is widespread support for the State Government's recent establishment of a remuneration model to support voluntary assisted dying practitioners in order to improve timely access for patients. It was also noted that Regional Access Support Scheme funding is available to facilitate voluntary assisted dying training for general practitioners.

However, stakeholders believe that a sustainable solution for ensuring adequate remuneration for voluntary assisted dying services requires the Australian Government, making changes to the Medicare Benefits Schedule (MBS). Stakeholders provided strong support for the idea that remunerating voluntary assisted dying practitioners through the MBS would expand workforce capacity, mitigating the risk of practitioner burnout and attrition. The Panel also noted that remuneration through the MBS will strengthen equity of access to voluntary assisted dying for those who cannot afford privately billed medical care.

Recommendation 7: That the State Government continue to advocate for the Australian Government to introduce Medicare Benefit Schedule items for voluntary assisted dying.

2.8 Substance administration, transport, and disposal

The Panel noted that the Act clearly describes how the authorised supplier and agent of the prescribed substance must act and that these intentional safeguards are working as intended. Some stakeholders suggested that education and policy improvements relating to the role of the contact person and the administration, transport and disposal of the substance were necessary. These improvements would ensure that all participants in the voluntary assisted dying processes fully understand their roles and responsibilities.

Recommendation 8: That the Department of Health:

- a) develops best practice resources for the storage, administration and disposal of the prescribed substance consistent with the Act, the *Misuse of Drugs Act 1981* and the *Medicines and Poisons Act 2014*.
- b) improves resources to assist patients in choosing and appointing a contact person, and additionally ensuring the contact person is fully informed and supported in carrying out their role.

2.9 Interpreters

The Panel received a detailed submission from Professionals Australia about the role of interpreters under the Act. The key concerns raised were the differences between translators and interpreters, the different skills involved in sight translation and verbal interpretation, the need for cultural awareness, provision for conscientious objection and the need for a best practice model for working with interpreters. The Panel is of the view that there is no hindrance in the Act to an interpreter, who must be accredited by a body approved by the CEO (section 162(2)), providing a translation of the written word (for example, in relation to the Written Declaration, section 42(6)). However, best practice would suggest that appropriately endorsed translated written material should be provided wherever possible.

Recommendation 9: That the Department of Health:

- a) provides translated versions of the Written Declaration for patients and interpreters to use in the voluntary assisted dying process when required.
- b) develops a best practice and culturally appropriate model for working with interpreters and translators in voluntary assisted dying.

2.10 Information sharing

The Panel noted confusion among stakeholders about the application of section 106 of the Act in relation to sharing patient information. The Act is clear that personal information obtained pursuant to a person's function under the Act cannot be directly or indirectly recorded, used or disclosed, subject to exceptions provided for under the Act (refer section 106 of the Act).

Importantly, section 106(f) allows for personal information to be shared where the patient gives written consent. The Panel suggests that improving understanding of section 106 will resolve ambiguity and maintain the safeguards intended by the Act.

Some stakeholders were of the view that expanding access to the Voluntary Assisted Dying Information Management System (VAD-IMS) would improve management and support for patients seeking voluntary assisted dying. However, it is clear that the VAD-IMS is specifically intended to be the operational system to enable the Voluntary Assisted Dying Board to have oversight and perform its monitoring functions under the Act. The VAD-IMS is not intended to be used as a clinical record.

Recommendation 10: That the Department of Health improve information and training material related to section 106 of the Act, to remove ambiguity and improve the confidence amongst practitioners and the wider workforce about information sharing, whilst maintaining the safeguards intended by the Act.

3. Summary of recommendations

The Act, as passed by the Parliament in 2019, does not require amendment. Improving policy and operational processes as well as education, training and information materials will increase both compliance with the Act and levels of access and support for eligible people and voluntary assisted dying providers.

Recommendation 1: That the Department of Health develop and implement a targeted strategy to improve community and health professionals' knowledge and awareness of voluntary assisted dying, the provisions of the Act and other end of life choices.

Recommendation 2: That the Department of Health reviews patient and health practitioner policies, education and training materials relating to the first request and the approved information (referred to in section 20(4)(b) of the Act) to ensure that understanding of how to make and respond to both voluntary assisted dying queries and first requests is maximised. This includes the obligations on all medical practitioners, including those with a conscientious objection who receive a first request, to comply with section 20 of the Act.

Recommendation 3: That the Department of Health:

- a) works with health, aged care, and other providers to clarify and strengthen the processes pertaining to the provision of access to voluntary assisted dying. This may be achieved by several mechanisms, including:
 - amending the Department of Health Managing Voluntary Assisted Dying Policy for government institutions
 - working with non-government institutions to minimise the potential harm caused by institutional conscientious objection.
- b) as a matter of priority, undertake work with medical practitioners and associated professional bodies to review procedures relating to the provision of relevant clinical information when requested, with patient consent, by voluntary assisted dying practitioners.
- c) ensures that voluntary assisted dying information, education and guidelines for medical practitioners specifically include a reference to the timely transfer of clinical information.

Recommendation 4: That the Department of Health ensures access to voluntary assisted dying for patients residing in regional areas is optimised through the Regional Access Support Scheme.

Recommendation 5: That the State Government continue to advocate for the Australian Government to amend the *Criminal Code Act 1995* (Cth) to improve equity of access to voluntary assisted dying.

Recommendation 6: That the Department of Health:

- a) continues to monitor and evaluate the voluntary assisted dying workforce including the Statewide Care Navigator Service and the Statewide Pharmacy Service.
- b) ensures that Health Service Providers are meeting their responsibilities as outlined in the Managing Voluntary Assisted Dying Policy including appropriately resourcing the voluntary assisted dying workforce.

Recommendation 7: That the State Government continue to advocate for the Australian Government to introduce Medicare Benefit Schedule items for voluntary assisted dying.

Recommendation 8: That the Department of Health:

- a) develops best practice resources for the storage, administration and disposal of the prescribed substance consistent with the Act, the Misuse of Drugs Act 1981 and the Medicines and Poisons Act 2014
- b) improves resources to assist patients in choosing and appointing a contact person, and additionally ensuring the contact person is fully informed and supported in carrying out their role.

Recommendation 9: That the Department of Health:

- a) provides translated versions of the Written Declaration for patients and interpreters to use in the voluntary assisted dying process when required.
- b) develops a best practice and culturally appropriate model for working with interpreters and translators in voluntary assisted dying.

Recommendation 10: That the Department of Health improve information and training material related to section 106 of the Act, to remove ambiguity and improve the confidence amongst practitioners and the wider workforce about information sharing, whilst maintaining the safeguards intended by the Act.

Appendix A. Voluntary Assisted Dying Review Panel

Dr Elissa Campbell - Consultant geriatrician with the North Metropolitan Health Service and palliative care specialist. Dr Campbell was a member of the Ministerial Expert Panel on Voluntary Assisted Dying and a member of the Implementation Leadership Team, which guided the implementation of the Act.

The Hon Dr Sally Talbot MLC – Member for South West Region. Dr Talbot was a member of the Joint Select Committee on End of Life Choices and a member of the Implementation Leadership Team, which guided the implementation of the Act.

Dr Simon Towler – Chief Medical Officer at the Department of Health. Dr Towler was a member of the Ministerial Expert Panel on Voluntary Assisted Dying and involved in the implementation of the Act in his previous role as End of Life Care Clinical Lead within the Department of Health.

Appendix B. Stakeholder engagement process

On 10 November 2023, a public consultation process was launched through the Department of Health's online consultation hub, Citizen Space.

Invitations to complete the online consultation were distributed widely including to health services, aged care providers, advocacy groups and peak bodies. To extend its reach, the Panel sent 97 letters to stakeholders representing key priority groups including the Aboriginal Health Council of Western Australia, Derbarl Yerrigan Health Service, WA Country Health Service and the Office of Multicultural Interests.

A total of 288 respondents provided responses to the survey, including 287 online and 1 hardcopy response. Responses represented health regions across WA, with the majority (75 per cent) received from the Perth metropolitan area, and the South West region having the second highest number of responses (9.4 per cent). The top 3 interest groups represented by responses were community members with a general interest in voluntary assisted dying (31.6 per cent), people who had someone close to them access voluntary assisted dying as their end of life choice (22.6 per cent) and health professionals who had supported a patient accessing voluntary assisted dying (9.6 per cent). The majority of respondents did not identify themselves as Aboriginal or Torres Strait Islander (98.5 per cent).

At the direction of the Panel, the survey outcomes were then analysed by the Department of Health and further investigated through targeted in-depth stakeholder interviews and focus groups by the Australian Centre for Health Law Research at the Queensland University of Technology (QUT).

A total of 8 semi-structured interviews and focus groups (comprising between 2 to 7 participants) were facilitated by QUT. QUT also considered the existing literature as part of their investigation. The Panel has published the QUT analysis alongside this report.

The Panel also received additional submissions throughout the review process and engaged in several stakeholder meetings with subject matter experts.

Appendix C. *Voluntary Assisted Dying Act* 2019 Review – Stage 1

Overview

In 2017, the Western Australian Parliament established the Joint Select Committee on End-of- Life Choices to inquire into the need for laws in WA to allow citizens to make informed decisions regarding their own end-of-life choices. The Committee conducted extensive consultation throughout its inquiry and tabled its *My Life, My Choice* report in both Houses of Parliament on 23 August 2018, recommending that the WA Government appoint an expert panel to undertake consultation to inform the drafting of voluntary assisted dying legislation.

In 2019, the Ministerial Expert Panel was established, chaired by Malcolm McCusker AC KC, and undertook comprehensive consultation to inform its recommendations about how the WA Government could develop safe, compassionate and workable legislation.

In August 2019, the *Voluntary Assisted Dying Bill 2019* was introduced into the Western Australian Parliament. Following 175 hours of debate, the Parliament passed the Bill on 10 December 2019, and it received Royal Assent on 19 December 2019. After an 18-month implementation period, the laws came into effect on 1 July 2021.

Section 164 of the *Voluntary Assisted Dying Act 2019 (WA)* (the Act), requires the Minister for Health to review its operation and effectiveness. This is the first time that the Act is being reviewed and the review process is being led by a three-member panel (Panel):

- Dr Elissa Campbell – Consultant geriatrician with the North Metropolitan Health Service and palliative care specialist. Dr Campbell was a member of the Ministerial Expert Panel on Voluntary Assisted Dying and a member of the Implementation Leadership Team, which guided the implementation of the Act
- Dr Sally Talbot MLC – Member for South West Region. Dr Talbot was also a member of the Joint Select Committee on End-of-Life Choices and a member of the Implementation Leadership Team
- Dr Simon Towler – Chief Medical Officer at the Department of Health. Dr Towler was a member of the Ministerial Expert Panel on Voluntary Assisted Dying and involved in the implementation of the Act in his previous role as End of Life Care Clinical Lead within the Department.

The Terms of Reference for the review of the Act (Review) are:

In carrying out the inaugural review of the Voluntary Assisted Dying Act 2019 (WA), the Panel should consider:

- the effectiveness and the operation of the Act, as passed by the Parliament in 2019, in providing for and regulating access to voluntary assisted dying; and
- the extent to which current processes provided under the Act are operating to support persons eligible for voluntary assisted dying in Western Australia.

The review is not seeking feedback on whether voluntary assisted dying should be precluded or whether there should be changes to eligibility criteria for patients or practitioners involved in the voluntary assisted dying process.

Why your views matter

The Panel members are experienced in issues affecting end-of-life care and are keen to receive your responses to the questions in this survey.

This survey will take 10 to 60 minutes to complete depending on the level of detail you choose to include.

The Review will be done in stages with the first stage involving this survey. This survey is an opportunity to identify priority issues to be further explored in the interviews, co-interviews, and focus groups during the second stage. As part of the Review process, your confidential responses to the survey questions may be used by the Panel, the Department of Health and the researchers involved in the second stage. During reporting on survey outcomes, de-identified quotes may be drawn from the survey responses.

About this survey

Throughout this survey we will refer to the process of voluntary assisted dying as VAD and the *Voluntary Assisted Dying Act 2019 (WA)*, as the Act.

The space provided for responses is limited. If your response exceeds the space provided, you can attach additional pages. If you provide any additional pages, please note the question numbers you are responding to.

Returning your completed survey

Please return your completed survey with any additional pages by posting it in the included pre-addressed envelope:

ATTN: End of Life Care Program Clinical Excellence Division
VAD Act Review Survey Response
PO Box 8172
PERTH BUSINESS CENTRE WA 6872

About you

The questions below are about you and will help us understand the range of people responding to this survey.

1. Are you responding to this survey as an individual or on behalf of an organisation? (Required)

Please tick only one item.

Individual Organisation (please specify)

Name of organisation: _____

2. What is your age? (Required) Please tick only one item.

15-24 25-34 35-44 45-54 55-64 65-74 75-84 85-94

95-104 105 and over Prefer not to say

3. How do you describe your gender? (Required) Please tick only one item.

Male Female Non-binary Prefer not to say I use a different term (please specify)

Please specify here: _____

4. Do you identify as Aboriginal and/or Torres Strait Islander? (Required) Please tick only one item.

Yes - Aboriginal

Yes - Torres Strait Islander

Yes - both Aboriginal and Torres Strait Islander

No

Prefer not to say

5. Are you a resident of Western Australia? (Required) Please tick only one item.

Yes No Prefer not to say

If yes, which region do you live in? Please tick only one item.

Perth Metropolitan (including Peel) Great Southern Goldfields Kimberley

Midwest Pilbara South West Wheatbelt Prefer not to say

If no, in which state or country do you live? _____

Some people will have more experience with VAD than others, including how the Act regulates the process in WA.

6. How confident are you in your understanding of the Act? (Required) Please tick only one item.

- Not at all confident
- Slightly confident
- Moderately confident
- Very confident
- Completely confident
- Prefer not to say

7. Which category BEST DESCRIBES your interest in the VAD Act? (Required) Please tick only one item.

- I am currently in the process of accessing VAD and have a coordinating practitioner
- I have previously tried to access VAD but was found ineligible
- I intend to request VAD in the near future
- Someone close to me is currently in the process of accessing VAD and has a coordinating practitioner
- Someone close to me has previously tried to access VAD but was found ineligible
- Someone close to me intends to request VAD in the near future
- Someone close to me accessed VAD as their end-of-life choice
- I am a member of the community and have a general interest in the discussion around VAD
- I have provided services under the Act (e.g. coordinating, consulting or administering practitioner, interpreter, authorised supplier or disposer etc.)
- I have worked in a role that directly supports VAD (e.g. Statewide Care Navigator Service, Health Service Provider VAD Leads, VAD Board etc.)
- I am from a professional organisation that represents those who provide services under the Act (e.g. union, professional college etc.)
- I am a member of a VAD advocacy organisation
- I am a health professional who has supported a patient accessing VAD
- I am a health professional who has not been directly involved with VAD (this includes practitioners have refused a first request for any reason described under the Act)
- I am a legal practitioner
- I am involved with law enforcement

Certain roles are designated by the Act. See below the roles designated by the Act.

Coordinating practitioner – The medical practitioner who accepts the patient’s first request (or the consulting practitioner for the patient who accepts a transfer of the role of coordinating practitioner).

Consulting practitioner – The medical practitioner who independently completes a consulting assessment for the patient.

Administering practitioner – The medical practitioner or nurse practitioner who administers the VAD substance to a patient.

Interpreter – A person who holds a NAATI credential, or a suitable qualification in interpreting from an Australian registered higher education provider or registered training organisation (RTO) and who has provided interpreting services for patient accessing VAD.

Contact person – The person appointed by a patient who has made a self-administration decision to carry out specific activities required by the law, including returning any unused or remaining VAD substance for disposal.

Authorised disposer – A registered health practitioner (pharmacist) who is authorised to dispose of the VAD substance.

8. If you have acted in any role/s designated by the Act, please tick these roles below. (Required) Please tick all that apply.

- | | |
|---|--|
| <input type="checkbox"/> I have not acted in a role designated by the VAD Act | <input type="checkbox"/> Interpreter |
| <input type="checkbox"/> Coordinating practitioner | <input type="checkbox"/> Contact person |
| <input type="checkbox"/> Consulting practitioner | <input type="checkbox"/> Authorised supplier |
| <input type="checkbox"/> Administering practitioner | <input type="checkbox"/> Authorised disposer |

The review panel may want more information on some of the themes that come up through the survey.

If you are open to sharing your thoughts with researchers who specialise in this area, you can provide your contact details below. The contact details you provide will remain strictly confidential but will be linked to the responses you’ve just given.

If you would like to provide your contact details but do not want them to be linked to this survey, you can email us instead: VADpolicy@health.wa.gov.au Not everyone who provides their details will be contacted to participate in the discussion process.

Name: _____

Email: _____

Phone Number: _____

Principles of the Act

Part 1 section 4 of the Act sets out the principles that a person (including the State Administrative Tribunal) exercising a power or performing a function or duty under the Act must have regard to.

The principles are intended to strike a balance between the importance of giving people genuine choice, while also recognising the need to protect individuals who may be subject to abuse. The principles will serve as a guide in interpreting and applying the Act but do not create any new obligations.

The principles of the Act

- a. every human life has equal value
- b. a person's autonomy, including autonomy in respect of end of life choices, should be respected;
- c. a person has the right to be supported in making informed decisions about the person's medical treatment, and should be given, in a manner the person understands, information about medical treatment options including comfort and palliative care and treatment
- d. a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life
- e. a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained
- f. a person should be encouraged to openly discuss death and dying, and the person's preferences and values regarding their care, treatment and end of life should be encouraged and promoted
- g. a person should be supported in conversations with the person's health practitioners, family and carers and community about treatment and care preferences
- h. a person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in Western Australia and having regard to the person's culture and language
- i. a person who is a regional resident is entitled to the same level of access to voluntary assisted dying as a person who lives in the metropolitan region
- j. there is a need to protect persons who may be subject to abuse or coercion
- k. all persons, including health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.

9. Based on your experience with VAD, do you consider that the principles of the Act have been observed and upheld in the first two years of the operation of the Act (section 4)?

Please tick only one item.

Yes No Unable to answer

If no, please explain which principle/s you are referring to and how they have not been observed and upheld.

Requesting access to Voluntary Assisted Dying and assessment of eligibility – The process

The process of requesting access to VAD and the assessment of eligibility is set out in Part 3 of the Act, sections 17 to 53 of the Act. The process is comprised of the following steps

- First Request
- First Assessment
- Consulting Assessment
- Written Declaration
- Final Request and Final Review

Section 53 of the Act says that a patient who seeks to access VAD may, at any time, decide not to proceed with the process, even after the request and assessment process has been completed.

The following questions (Q10 to Q14) will ask for your comment on each of the steps for requesting access to VAD and the assessment of eligibility.

First Request as set out in section 18 to 23 of the Act

The First Request is a request for VAD that is made to a medical practitioner (a doctor) during a medical consultation. This request must be clear and unambiguous, made by the person either in person or by means of audio-visual technology, either verbally or by gestures or other means of communication available to that person.

The medical practitioner will decide to accept or refuse the First Request. They might refuse because they do not agree with VAD (they have a conscientious objection to VAD – section 9 and section 20(5)) or because they aren't eligible or able to accept the request. Whether they accept or refuse the First Request the medical practitioner must provide the patient with the Approved Information for a Person Making a First Request for VAD information sheet.

If English is not the patient's first language or they have communication difficulties, an interpreter or communication aid can be used to make the First Request.

10. What comment do you have, if any, regarding the operation and effectiveness of the First Request during the first two years of operation under the Act (sections 18 to 23)?

In your response, indicate what is working well and any challenges.

First Assessment as set out in section 24 to 30 of the Act

Once the medical practitioner accepts the First Request, they become the Coordinating Practitioner for the patient. In this role they will coordinate the VAD process for the patient. The first step for the Coordinating Practitioner is to formally assess the patient's eligibility for VAD to make sure they meet all the criteria required by the Act. This assessment is called the First Assessment.

11. What comment do you have, if any, regarding the operation and effectiveness of the First Assessment during the first two years of operation under the Act (sections 24 to 30)?

In your response, indicate what is working well and any challenges.

If the outcome of the First Assessment is that the patient is eligible for VAD, the Coordinating Practitioner will refer them to another medical practitioner for assessment. This other medical practitioner becomes the Consulting Practitioner for the patient and will independently assess the patient's eligibility for VAD. This assessment is called the Consulting Assessment.

Consulting assessment as set out in section 31 to 41 of the Act

12. What comment do you have, if any, regarding the operation and effectiveness of the Consulting Assessment during the first two years of operation under the Act (sections 31 to 41)?

In your response, indicate what is working well and any challenges.

Written Declaration as set out in section 42 to 46 of the Act

13. What comment do you have, if any, regarding the operation and effectiveness of the Written Declaration during the first two years of operation under the Act (sections 42 to 46)?

In your response, indicate what is working well and any challenges.

Final Request and Final Review as set out in section 47 to 53 of the Act

A patient who has made a Written Declaration may make a final request to the Coordinating Practitioner for VAD. The Final Request cannot be made before the end of the designated period of nine days, which begins on the day of the First Request. If both the Coordinating Practitioner and the Consulting Practitioner believe the patient will die or lose capacity to make decisions about VAD before the end of the designated period, the patient may be allowed to access the VAD substance sooner. The VAD substance is the medication that will result in the patient's death.

The Final Request helps to ensure that the patient's decision to access VAD is enduring and hasn't changed. If the patient makes a valid Final Request the Coordinating Practitioner will then start the Final Review process. The Final Review requires the Coordinating Practitioner to check that the request and assessment process has been completed in accordance with the Act. This means that the Coordinating Practitioner must make sure that the patient still has decision-making capacity in relation to VAD, is acting voluntarily and without coercion, and still wants to access VAD.

14. What comment do you have, if any, regarding the operation and effectiveness of the Final Request and Final Review during the first two years of operation under the Act (sections 47 to 53)?

In your response, indicate what is working well and any challenges.

Requesting access to Voluntary Assisted Dying and assessment of eligibility – fundamental objectives and questions for health practitioners

The process of requesting access to VAD and the assessment of eligibility is set out in Part 3 of the Act, sections 17 to 53 of the Act. The process is comprised of the following steps

- First Request
- First Assessment
- Consulting Assessment
- Written Declaration

Section 53 of the Act says that a patient who seeks to access VAD may, at any time, decide not to proceed with the process, even after the request and assessment process has been completed.

The following questions (Q15 to Q20) will ask for your comment on a range of fundamental objectives of the Act and specific questions for Health Practitioners.

VAD must be completely voluntary in all respects

A fundamental objective in the Act is that participation in VAD must be completely voluntary in all respects (section 16(1)(e)). Throughout the stages of the VAD process, the Act includes safeguards to ensure that the person requesting VAD is acting voluntarily and without coercion.

These safeguards include, but are not limited to:

- Patient to make first request (section 18(2))
- No obligation to continue (sections 19, 53)
- Exclusion of witnesses who are family members, beneficiaries or practitioners (sections 43(2), 62(3))
- Exclusion of practitioners who are family members and beneficiaries (sections 26(5), 37(5), 54(1) (c) & (d))
- Ensuring the patient is acting voluntarily, without coercion section 59(5)(b),
- Practitioner to certify patient's voluntary act without coercion section 61(2)(b)
- Application for review by State Administration Tribunal of voluntariness or coercion in certain decisions section (84(1))
- Offence to induce another person to request or access VAD (section 100)
- Offence to induce another person to self-administer a prescribed substance (section 101).

15. Based on your experience with VAD, to what extent have the above safeguards operated effectively in the first two years of the Act to ensure that the person requesting VAD is acting voluntarily and without coercion?

In your response, describe what is working well and any ways in which you think particular safeguard/s could operate more effectively.

Provision of information to the patient

A fundamental objective of the Act is that the person's decision is well informed. Throughout the stages in the VAD process, the Act requires the medical practitioner, coordinating practitioner and consulting practitioner to inform the patient about a number of matters related to the VAD process.

These requirements include, but are not limited to:

- Providing approved information at first request (section 20(4)(b))
- Information to be provided if patient assessed as meeting eligibility criteria (section 27 and 38)
- Information to be given for prescribing substance (section 69).

16. Based on your experience with VAD, to what extent during the first two years of the operation of the Act has the objective that the person's decision is well informed been upheld by the requirements listed above?

In your response, describe what is working well and any ways in which you think this objective could operate more effectively.

Communication of decision and outcomes to patient

A fundamental objective of the Act is that the medical practitioner or coordinating practitioner is professionally obligated not to unduly delay a patient's access to VAD. Throughout the stages of the VAD process, the Act requires the medical practitioner and coordinating practitioner to notify the patient of their decision and assessment outcome(s) as soon as practicable or within a specified time limit.

These requirements include, but are not limited to:

- Response within two business days (sections 20(4) and 31(4))
- Immediate response if practitioner has a conscientious objection (section 20(5) and 31(5))
- Informing as soon as practicable after completion of first or consulting assessment (section 29(1) and 40(1))

17. To what extent has this objective been upheld by the requirements listed above during the first two years of the operation of the Act?

In your response, indicate what is working well and any ways in which you think this objective could operate more effectively.

Assessment of patient's decision-making capacity

A patient's decision-making capacity is assessed at several stages throughout the VAD process under the Act. The staged approach reflects that the patient's capacity to make decisions about VAD may fluctuate, and that in order to access VAD there must be enduring decision-making capacity.

For a patient to progress through each stage of the VAD process under the Act, the person's request for access must also be enduring (sections 16(1)(f), 51(3)(f), 59(5)(c), 61(2)(b) and 62(3)(a)).

18. To what extent have the assessments to ensure the patient's decision-making capacity and choice to access VAD is enduring operated effectively in the first two years of the Act?

In your response, indicate what is working well and any challenges.

Unambiguous first request (question for health professionals)

Section 18 provides that a person may make a First Request for access to VAD to a medical practitioner. This request must be clear and unambiguous, made by the person either in person or by means of audio-visual technology, either verbally or by gestures or by other means of communication available to that person.

This reflects the requirement that a request for access to VAD must be distinguished from a request for information about VAD.

19. What, if any, difficulties have you experienced during the first two years of the operation of the Act with distinguishing a request for access to VAD from a request for information about VAD?

In your response, indicate how these could be addressed.

Referral for determination (question for health professionals)

Sections 26 and 37 set out the circumstances in which a coordinating practitioner and consulting practitioner respectively, must refer the patient for a determination (opinion) on one or more of the matters set out under the eligibility criteria under section 16(1)(c), (d) or (e).

Sections 26 (1) and (2) and sections 37 (1) and (2) provide that where the coordinating practitioner or consulting practitioner cannot determine whether the patient's disease, illness or medical condition meets the eligibility criteria, or whether the patient has decision making capacity in relation to VAD under the eligibility criteria, the coordinating practitioner must refer the patient to a registered health practitioner with the appropriate skills and training to make that determination.

Sections 26(3) and 37(3) provide that where a coordinating practitioner or consulting practitioner cannot determine whether the patient is acting voluntarily and without coercion, they must refer the patient to a person with the appropriate skills and training to make that determination (i.e. experienced registered health practitioners, health care workers including social workers and police officers).

20. What, if any, difficulties have you experienced with making a referral for determination during the first two years of the operation of the Act?

In your response, indicate how these could be addressed.

Administration of voluntary assisted dying substance and Contact Person

Part 4 sections 55 to 63 of the Act sets out the requirements for the administration of the VAD substance. The VAD substance is the medication used to bring about VAD.

The patient will need to decide, with the help of their Coordinating Practitioner, if they will self-administer the VAD substance or if appropriate, have an Administering Practitioner administer it to them. The Administering Practitioner will usually be the Coordinating Practitioner. In some cases, the role of Administering Practitioner for the patient can be transferred to another eligible medical practitioner or nurse practitioner (section 63).

If the patient decides to self-administer the VAD substance, they must appoint a Contact Person before the Coordinating Practitioner can prescribe the VAD substance. Part 4 section 64 to 68 of the Act sets out the requirements, processes and role of the Contact Person.

More information about self-administration and practitioner administration

Self-administration - Self-administration of the VAD substance requires the person to prepare and ingest the substance by swallowing or via a percutaneous endoscopic gastrostomy (PEG) or nasogastric (NG) tube. The patient needs to be able to complete these actions entirely by themselves and cannot be assisted with preparing the substance (which includes decanting, mixing etc.) or with the physical act of ingesting the substance. This includes assistance with using their PEG or NG tube.

Practitioner administration - A practitioner administration decision can only be made if the Coordinating Practitioner advises the patient that self-administration of the VAD substance is not appropriate for them. This will be due to one or more reasons, including:

- the patient is unable to self-administer the substance
- the patient has concerns about self-administering the substance
- the self-administering method is unsuitable for the patient.

21. What comment do you have, if any, regarding the operation and effectiveness of the administration of the VAD substance during the first two years of operation under the Act (sections 55 to 63)?

In your response, indicate what is working well and any challenges.

22. What comment do you have, if any, regarding the operation and effectiveness of the contact person role during the first two years of operation under the Act (sections 64 to 68)?

In your response, indicate what is working well and any challenges.

Prescribing, supplying and disposing of voluntary assisted dying substance

Part 4 sections 69 to 81 of the Act sets out the requirements for the prescription, supply and disposal of the VAD substance. The VAD substance is the medication used to bring about VAD.

The Coordinating Practitioner prescribes the VAD substance. They are required to give the patient certain information about the substance before prescribing the VAD substance. The Coordinating Practitioner will give the prescription directly to the Authorised Supplier at the Western Australian Voluntary Assisted Dying Statewide Pharmacy Service (sections 69 to 70).

If the patient has decided to self-administer, the Authorised Supplier can supply the VAD substance directly to the patient, their Contact person or to someone else collecting the substance on the patient's behalf. Written information about the VAD substance (including instructions for storage and use) will be provided by the Authorised Supplier and given to the person who collects the substance. If the patient has decided to have the VAD substance administered to them by a medical practitioner or nurse practitioner (known as the Administering Practitioner), the Authorised Supplier will supply the substance directly to the Administering Practitioner (who will take responsibility for the substance until it is used). (Sections 71-74, 80 and 81)

Authorised Disposers are registered health practitioners who have been authorised by the Director General of Health (as CEO) to legally dispose of the VAD substance. In WA, Authorised Disposers include registered pharmacists that hold specifically identified roles. Sections 75 to 79 describe the requirements of for disposal of the VAD substance.

23. What comment do you have, if any, regarding the prescription and supply processes for the VAD substance during the first two years of operation under the Act (sections 69 to 74, 80 and 81)?

In your response, indicate what is working well and any challenges.

24. What comment do you have, if any, regarding the disposal processes for the VAD substance) during the first two years of operation under the Act (sections 75 to 79)? In your response, indicate what is working well and any challenges.

State Administrative Tribunal, Offences, the Voluntary Assisted Dying Board and Complaints

The following questions cover Part 5 – Review by Tribunal (sections 83 to 98), Part 6 – Offences (sections 99 to 108), Part 8 – Protection from liability (section 113 to 115), Part 9 – Voluntary Assisted Dying Board (section 116 to 155), reporting requirements and complaints (sections 118, 171, 172).

If you are unsure about any of the questions in this section, please select the “unable to answer” option.

The State Administrative Tribunal (SAT) is an independent body that makes and reviews a range of administrative, commercial and personal matters in WA. Part 5 (sections 83 to 98) of the Act allows for certain decisions made during the VAD assessment process to be reviewed by SAT. These are known as reviewable decisions and include:

- a decision that the patient has or has not been ordinarily resident in WA for at least 12 months prior to requesting VAD
- a decision that the patient does or does not have decision-making capacity in relation to VAD
- a decision that the patient is or is not acting voluntarily and without coercion

The State Administrative Tribunal (SAT)

25. Before this survey, I was aware that the SAT can review certain decisions made during the eligibility assessment process.

Please tick only one item.

Yes No Unable to answer

26. I have been involved in a SAT proceeding relating to VAD.

Please tick only one item.

Yes No Unable to answer

27. What comment do you have, if any, regarding SAT’s role in reviewing of certain decisions during the first two years of operation under the Act (sections 83 to 98)?

Offences

The Act provides protections for individuals involved in the VAD process but also clearly outlines offences and circumstances that may be considered professional misconduct or unprofessional conduct (Part 6, sections 99 to 108). Penalties for committing an offence under the Act can include monetary fines and/or imprisonment.

28. Before this survey, I was aware that there are several offences under the Act that can result in a person receiving a fine or a prison sentence.

Please tick only one item.

Yes No Unable to answer

29. I have been involved in an offence process or proceeding relating to VAD.

Please tick only one item.

Yes No Unable to answer

30. What comment do you have, if any, regarding the operation and effectiveness of the Offence provisions during the first two years of operation under the Act (sections 99 to 108)?

Part 8 (section 113 to 115) of the Act establish and set out protections for persons assisting access to VAD or present when substance is administered; persons acting in accordance with the Act; and for certain persons who do not administer lifesaving treatment.

Protection from liability

31. What comment do you have, if any, regarding the operation and effectiveness of the protections from liability during the first two years of operation under the Act (sections 113 to 115)?

The Voluntary Assisted Dying Board

Part 9 (sections 116 to 155) of the Act establish and set out the role and powers of the Voluntary Assisted Dying Board (Board). The Board is established for the purpose of ensuring proper adherence to the legislation and to recommend safety and quality improvements. The Board will have mainly advisory and monitoring functions in relation to VAD. It does not have an investigatory or enforcement role.

32. Before this survey, I was aware of the Board.

Please tick only one item.

Yes No Unable to answer

33. What comment do you have, if any, regarding the function of the Board during the first two years of operation under the Act (sections 116 to 155)?

Reporting to the Board (for those providing services under the Act)

Throughout the stages of the VAD process, the Act includes reporting requirements to notify the Board. These requirements are intended to ensure that the Board is notified from the outset of a person's request to participate in VAD, and to enable the Board to monitor that the correct process is being followed in each case. Further, it enables the Board to maintain complete and accurate statistics of participation in VAD in Western Australia.

Reporting requirements to the Board in the Act include but are not limited to, section 22, section 29(2), section 33(1), section 40(2), section 46, section 50(1), section 74(3), section 76(3), section 78(3), and section 82(2).

34. What comment do you have, if any, regarding how the reporting requirements listed above are working in practice, during the first two years of operation under the Act?

Complaints

The Act does not create a specific complaints framework. The Act amended the Health and Disability Services (Complaints) Act 1995 so that complaints about individuals or organisations that provide health, disability or mental health services in relation to VAD can be made to the Health and Disability Services Complaint Office (HaDSCO) (section 171 to 172).

Concerns about the conduct or performance of a registered health practitioner can be raised with the Australian Health Practitioner Regulation Agency (Ahpra). Concerns about a health professional not meeting the requirements of the Act can be raised with the Board (section 118).

35. Before this survey, I was aware that that I can make a complaint to an organisation such as HaDSCO, Ahpra or the Board.

Please tick only one item.

Yes No Unable to answer

36. I have made or intend to make a complaint to one these organisations.

Please tick only one item.

Yes No Unable to answer

37. What comment do you have, if any, regarding the availability and appropriateness of the Complaints processes (as described above) during the first two years of operation under the Act?

In your response, indicate what is working well and any challenges.

Use of interpreter services

The Act allows an interpreter to be engaged throughout the VAD process. The interpreter must meet the requirements set out in section 162 and certify that they provided a true and correct translation (section 42(6) – written declaration).

38. What comment do you have, if any, regarding the operation and effectiveness of the interpreter requirements of the Act during the first two years of its operation (section 162)?

In your response, indicate what is working well and any challenges.


Other matters and General feedback

39. What, if any, other matters would you like to raise relating to the operation and effectiveness of the Act during the first two years of its operation?

Appendix D. Principles of the Act

Section 4 of the Act

- (1) A person exercising a power or performing a function under this Act must have regard to the following principles —
- a) every human life has equal value;
 - b) a person's autonomy, including autonomy in respect of end of life choices, should be respected;
 - c) a person has the right to be supported in making informed decisions about the person's medical treatment, and should be given, in a manner the person understands, information about medical treatment options including comfort and palliative care and treatment;
 - d) a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life;
 - e) a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained;
 - f) a person should be encouraged to openly discuss death and dying, and the person's preferences and values regarding their care, treatment and end of life should be encouraged and promoted;
 - g) a person should be supported in conversations with the person's health practitioners, family and carers and community about treatment and care preferences;
 - h) a person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in Western Australia and having regard to the person's culture and language;
 - i) a person who is a regional resident is entitled to the same level of access to voluntary assisted dying as a person who lives in the metropolitan region;
 - j) there is a need to protect persons who may be subject to abuse or coercion;
 - k) all persons, including health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.
- (2) In subsection (1), the reference to a person exercising a power or performing a function under this Act includes the Tribunal exercising its review jurisdiction in relation to a decision made under this Act.



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