

Voluntary Assisted
Dying Review Board

Report of operations

June to December 2019

This is the second report from the independent Voluntary Assisted Dying Review Board.

It details:

- activity since the commencement of the *Voluntary Assisted Dying Act 2017* on 19 June to 31 December 2019
- key lessons and reflections drawn from case reviews and feedback.

By law, the Board is required to report to Parliament every six months for the first two years. The next report will be tabled by **August 2020** and will cover the reporting period 1 January to 30 June 2020.

After the first two years, the Board will report each financial year.

More information

bettersafercare.vic.gov.au/vad

To receive this publication in an accessible format phone 03 9096 1384, using the National Relay Service 13 36 77 if required, or email info@safercare.vic.gov.au

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Foreword

In the first six months of operation, Victoria's *Voluntary Assisted Dying Act 2017* has provided another choice for people who are nearing the end of their life. During this period 136 people commenced the assessment process through the Voluntary Assisted Dying Portal. Through feedback from the people who have requested voluntary assisted dying, their families, carers and medical practitioners, we have heard how voluntary assisted dying is providing another choice in end of life care.

The *Voluntary Assisted Dying Act 2017* (the Act) has operated safely in the first six months.

Providing important reassurance to the community, the Voluntary Assisted Dying Review Board (the Board), which is responsible for reviewing every application, confirmed that all cases to date were compliant with the Act. That is, everyone who accessed voluntary assisted dying met the strict eligibility requirements and went through the correct checks.

In implementing the Act, the Board planned and prepared for the estimated projections on permit activity. This was based on Victoria's population size and the activity and information from other countries who have implemented similar, but far from identical, laws. In the first six months, 136 people commenced the assessment process through the Voluntary Assisted Dying Portal. This demonstrates the Act has struck a balance between being strict with compliance, while still accessible to those who want this choice.

However, not everyone who requested voluntary assisted dying was able to proceed. It is an important lesson for everyone involved in the process – such as those providing information to the public, those who are assisting the applicant, through to the person seeking to obtain the permit – that information provided needs to be clear. This is to ensure everyone fully understands the eligibility requirements and that time and thoughtful planning is needed. We have provided more of these key lessons and reflections throughout this report.

The Board collects a wide range of information beyond permit numbers, including feedback from those people who have requested to access voluntary assisted dying and their nominated contact person and medical practitioners.

From this we are beginning to learn how voluntary assisted dying is being accessed, by who, and how the process can be improved to help Victorians approaching end of life. To help understand more from the information and data collected, we will be finalising an approach to future research this year.

A note on data and privacy

While this is the Board's second report, it is the first to detail activity under the Act. As always, we have been careful to protect the anonymity of those people who have accessed voluntary assisted dying, and the health professionals who provide support. To that end, data included in this report is de-identified and reported at a level which preserves privacy.

Feedback

The Board welcomes feedback and improvement suggestions to aid the safe operation of voluntary assisted dying in Victoria. Please email VADboard@safecare.vic.gov.au

"I am grateful for the time we had together and being able to prepare our goodbyes."

— Contact person

Thank you

On behalf of the Board, I thank the families, carers and nominated contact people who have supported loved ones through their death. We also thank the medical practitioners and health professionals who provided their support and expertise to enable eligible Victorians to access voluntary assisted dying.

My thanks also to the dedicated and compassionate members of the Board, the Safer Care Victoria secretariat, the Statewide Pharmacy Service, the Statewide Care Navigator Service and the various Department of Health and Human Services (DHHS) teams that support the Act's operation.

A handwritten signature in black ink, appearing to read 'Betty King', with a stylized flourish at the end.

Betty King

Chairperson

Voluntary Assisted Dying Review Board

Snapshot

Requests received from 19 June to 31 December 2019

| STAGE | | STATUS | NUMBER | TOTAL |
|---|------------------------------------|---|--------|------------|
| Eligibility | First assessment | Eligible | 135 | 136 |
| | | Ineligible | 1 | |
| | Consulting assessment | Eligible | 100 | 102 |
| | | Ineligible | 2 | |
| Permit applications | Self-administration permit | Approved | 70 | 70 |
| | | Not approved | 0 | |
| | Practitioner administration permit | Approved | 11 | 11 |
| | | Not approved | 0 | |
| | Withdrawn | Reasons for withdrawal may include administrative error or confirmation of death by means other than voluntary assisted dying | | 19 |
| | Medications dispensed | For self-administration | | 57 |
| For administration by a practitioner | | | 9 | |
| Confirmed deaths (as notified by Births, Deaths and Marriages) | Medication was administered | Medication was self-administered | 43 | 52 |
| | | Medication was administered by a practitioner | 9 | |

Eligibility criteria to access voluntary assisted dying

To be eligible for voluntary assisted dying, the person needs to show evidence they:

- have an incurable and advanced disease, illness or medical condition that is expected to cause death within six months (or within 12 months for a neurodegenerative condition)
- are experiencing suffering, which the person considers intolerable
- have decision-making capacity in relation to voluntary assisted dying
- are an adult, 18 years old or over
- are an Australian citizen or permanent resident who has lived in Victoria for at least the past 12 months.

Teams involved in voluntary assisted dying in Victoria

Victoria's *Voluntary Assisted Dying Act 2017* (the Act) commenced on 19 June 2019. To ensure a smooth implementation and safe operation of the Act, several different teams were established, each with a distinct role. These teams worked closely with other agencies, such as Births, Deaths and Marriages Victoria, the Australian Healthcare Practitioner Regulation Agency, the Coroners Court of Victoria and Victoria Police.

The Voluntary Assisted Dying Review Board

The Board was appointed in July 2018 to independently review all cases of voluntary assisted dying. For a list of inaugural Board members, see page 12.

The Board retrospectively reviews all cases of voluntary assisted dying to ensure compliance with the Act. It also monitors and reports on all activity under the Act.

The Board does not have an investigatory or punitive role, or an approval function. Instead, the Board may refer any identified issues to an appropriate investigator or regulator.

The Board meets monthly, presided by the Chairperson or Deputy Chairperson.

More detail on the Board's role and functions is available at bettersafercare.vic.gov.au/vad

The Board is supported by Safer Care Victoria, which provides the Board secretariat and administrative day-to-day operational support. This includes:

- receiving requests to access the Voluntary Assisted Dying Portal, and supporting users
- receiving and progressing forms
- preparing Board reports and case reviews
- liaising with the nominated contact people, as well as agencies involved in supporting the voluntary assisted dying process.

Contact: VADBoard@safercare.vic.gov.au

Statewide services

- **The Statewide Care Navigator Service.** This service provides information and support to the community, health practitioners and health services across Victoria.

Contact: vadcarenavigator@petermac.org

- **The Statewide Pharmacy Service.** Based at Alfred Health, this service provides support and information on the dispensing process. It is the only dispensary for the voluntary assisted dying medications. It offers a delivery, collection and support service to people accessing voluntary assisted dying and their medical practitioners.

Contact: statewidepharmacy@alfred.org.au

End of Life Care Team, DHHS

In addition to overseeing the statewide services, this team co-ordinates:

- **Voluntary assisted dying medical practitioner training.** All medical practitioners are required to complete training before requesting access to the portal.
- **Policy and guidance** for health services, health professionals and the community to support voluntary assisted dying.

Contact: EndofLifecare@dhhs.vic.gov.au

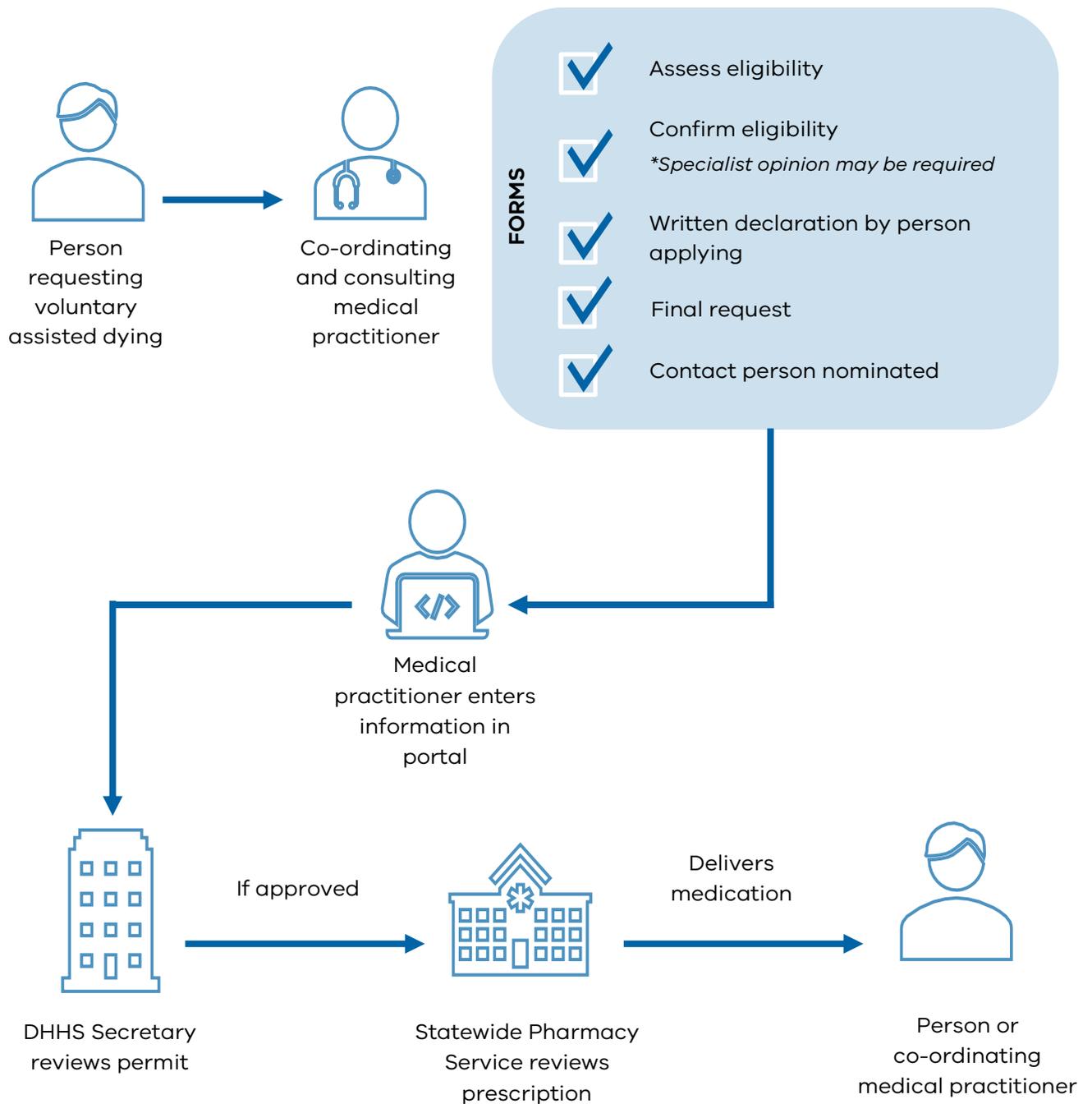
Safer Prescribing Team, DHHS

This team facilitates the process for permit application reviews by the DHHS Secretary which then allows medication to be dispensed.

Contact: dpcs@dhhs.vic.gov.au

The voluntary assisted dying process

Access to voluntary assisted dying has strict eligibility requirements and is an involved process. The below diagram simply explains the steps a person, their medical practitioners and nominated contact person must take to apply for and obtain a permit. The full process is detailed in the Act.



Supporting medical practitioners

VOLUNTARY ASSISTED DYING TRAINING

The online training platform helps medical practitioners understand the requirements for accessing voluntary assisted dying for those who make a request.

Medical practitioners must complete and pass the training before undertaking an assessment as a co-ordinating or consulting medical practitioner.



365 medical practitioners registered for training



taking on average **4 hours** to finish

KEY LESSONS AND REFLECTIONS

Connecting with broader end of life care options

Voluntary assisted dying is only one option at the end of life and may arise in the context of other aspects of care. Conversations should be comprehensive and consider all options. Victoria's *End of Life and Palliative Care Framework* is a useful resource.

Correcting perceptions about timeframe

The Board is improving how it collects and analyses feedback, particularly from medical practitioners on the voluntary assisted dying process, including the time it takes to complete training.

The training has been developed to ensure sufficient time is dedicated to understanding the requirements in the Act. Training takes an average of four hours, while applying for access to the portal takes 15 minutes. The Board acknowledges those medical practitioners who have taken the time to complete the training.

Peer support

Trained medical practitioners and health service staff involved in voluntary assisted dying as part of their roles can access specialist communities of practice. The aim of these networks is to share experiences, lessons and provide peer support.

Medical practitioners who have undertaken voluntary assisted dying training and wish to join the community of practice should contact vadcommunity@westvicphn.com.au

Health service staff involved in voluntary assisted dying as part of their roles and wish to join the community of practice should contact vadcarenavigator@petermac.org

Information for health professionals

- To download information and resources about voluntary assisted dying, go to www2.health.vic.gov.au/voluntary-assisted-dying
- Specific user manuals are also contained within the training platform.
- To access *Victoria's End of Life and Palliative Care Framework*, go to www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/palliative-care/end-of-life-and-palliative-care-framework

Supporting voluntary assisted dying requests

VOLUNTARY ASSISTED DYING PORTAL

Once training is completed, medical practitioners can register in the Voluntary Assisted Dying Portal. The portal was activated on 19 June 2019 for medical practitioners to submit online forms and permit requests on behalf of those people requesting voluntary assisted dying.



134 medical practitioners registered in the portal

33% of trained medical practitioners are located outside metro Melbourne



649 individual forms submitted through portal

KEY LESSONS AND REFLECTIONS

Proving Victorian residency

Some people have found it difficult to prove they are an Australian citizen/permanent resident who has lived in Victoria for at least 12 months.

While these requirements can pose a challenge, they are requirements of the Act and must be established before voluntary assisted dying can be accessed. If a person is considering voluntary assisted dying it is worth obtaining this evidence early.

More information can be found at www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/community-consumer-information/voluntary-assisted-dying-process/conditions

Finding a medical practitioner to assist

We know that some families and loved ones have found it difficult to find a medical practitioner who has undertaken the training and is willing to assist. The Board expected that the number of trained medical practitioners would grow over time.

The Board is pleased to see the number of medical practitioners who have completed training in voluntary assisted dying has increased across all regions of Victoria. With the assistance of the Statewide Care Navigator Service, the Board expects access to trained medical practitioners will become easier in time.

“The family felt that finding a medical practitioner who would be involved in the process took a long time. However, the process went smoothly once established.”
— **Contact person**

Expanding the Care Navigator Service

The Statewide Care Navigator Service has proved a valuable support mechanism and education provider for individuals, their loved ones, medical practitioners and health services. The service is expanding with a focus on developing regional networks.

“I would like to praise the care and compassion of all involved specifically the positive support received from the care navigators through the process.”
— **Contact person**

Supporting nominated contact people

Being the nominated contact person may have a great impact on people as they support their loved one through the process of voluntary assisted dying. Some have described the experience as very confronting and challenging.

The Board, through the secretariat, contacts the nominated contact person firstly to gain any information they are willing to share about the process. Secondly, to ensure they and their loved ones know how to seek support from grief and bereavement services.

“Being the contact person was a huge responsibility and a very intense experience.”
— Contact person

Information for the community

- For more information: www2.health.vic.gov.au/voluntary-assisted-dying
- Australian Centre for Grief and Bereavement: 1800 642 066
- GriefLine: 1300 845 745
- Lifeline: 13 11 14

Seeking specialist opinion for eligibility or decision-making capacity

The co-ordinating medical practitioner **only** needs to seek a further opinion from a specialist registered medical practitioner when they are unsure of a person’s diagnosis or prognosis, or when the person has a neurodegenerative condition with a prognosis of six to 12 months.

A specialist opinion is required to come from a third medical practitioner, who does not have to complete the training or be registered in the portal, and they cannot be the consulting medical practitioner.

A specialist opinion may also be sought from a registered health professional if the co-ordinating medical practitioner is unable to determine the person’s decision-making capacity in relation to voluntary assisted dying.

Understanding why some permits are declined or forms returned requesting further information

Some permit requests were initially declined due to errors in the permit application form. Some forms were returned for resubmission due to missing information or eligibility documentation.

Medical practitioners can help avoid this by:

- ensuring all eligibility evidence is included initially, and is consistently correct, especially:
 - the person’s prognosis (in addition to their diagnosis)
 - proof of residency
- ensuring information is correct and consistent, especially:
 - the person’s name and address and date of birth
 - the medicines being requested in the permit (correct dose and spelling)
- submitting all forms within mandated periods
- ensuring all uploaded documents, such as written declaration and contact person appointment forms, are complete with all required signatures and dates, and meet the timelines required in the Act.



83% of cases required forms to be returned for clarification or provision of missing eligibility information

Reviewing and learning

BOARD CASE REVIEWS

The Board retrospectively reviews cases each month. Board members discuss all cases and determine compliance with the Act. They also review potential barriers and improvement opportunities.

No cases were referred for investigation in this reporting period.

 **100% cases compliant**

“Because of the [voluntary assisted dying] medication, the family was able to experience saying their goodbyes to an alert person – not a person suffering. The process was quick, dignified and gentle. It was comforting to those involved that the person had their wishes fulfilled.”
— **Contact person**

OPPORTUNITIES FOR IMPROVEMENT

Under the Act, the Board may make recommendations to improve the operation of the Act. In this reporting period, the Board has not made any recommendations.

However, the Board has identified potential ways to improve the operation of the voluntary assisted dying process and updated the resources available to health professionals and those people wanting to access it. These insights were gained from case reviews, evidence, feedback from individuals, medical practitioners and nominated contact people, as well as letters from the Victorian public. We share what we learn with DHHS and other agencies involved to improve the ongoing operation of the Act.

KEY LESSONS AND REFLECTIONS

Allowing time and careful planning

Voluntary assisted dying is not an emergency medical procedure and takes time and thoughtful planning.

The process can take several weeks. This is because it takes time to gather all the required documentation and evidence, complete the legal assessments and forms and submit everything through the portal.

“We were worried about how long the process took and that due to the physical deterioration that they might not be able to swallow the medication.”
— **Contact person**

Understanding time to death

Once someone takes the medication the time to death can vary.

After taking the medication, the person will start feeling drowsy within minutes. Unconsciousness is expected to occur within 10 to 20 minutes, and death will occur within one to two hours for the majority of people. In some cases, death may take longer.

As everyone is different, these timeframes are only estimates. The Statewide Pharmacy Service team discuss this in further detail in their visits.

“The pharmacy service were angels – I cannot thank them enough for their support. They went above and beyond and were calm, caring and obliging towards my family member and myself.”
— **Contact person**

Understanding the Death Certificate and the Medical Certificate of Cause of Death (MCCD)

A MCCD is written by a medical practitioner on confirmation of death. It includes the date, time, and cause of death and information on voluntary assisted dying status. Funeral directors cannot inter or cremate a body without a MCCD.

It is a requirement of the Act that the medical practitioner makes a notification to the Coroner of a voluntary assisted dying death via the Coronial Admissions and Enquiries Office. In normal circumstances a coronial investigation will **not** be required.

A death certificate is provided to the next of kin from Births, Deaths and Marriages Victoria weeks to months after a death. The certificate does **not** include any details about voluntary assisted dying and can be used for insurance and other legal requirements.

Following up with medical practitioners and nominated contact people

The secretariat team telephones the nominated contact person for every case where the voluntary assisted dying medication is dispensed. This is to seek feedback on the process and ensure any unused medication is returned.

In future, the Board intends to request feedback from medical practitioners involved in the process as well as the nominated contact person for anyone who has had a permit approved.

“The experience was peaceful and dignified. They were granted their final wish of dying the way they wanted.”

— **Contact person**

Interaction with Commonwealth Law

The Board is concerned about the impact of sections 474.29A and 474.29B of the *Commonwealth Criminal Code 1995* as amended by the *Criminal Code Amendment (Suicide Related Material Offences) Act 2005* on voluntary assisted dying.

This commonwealth law means that it is an offence to use a carriage service (such as telephone or telehealth) for suicide-related material (which may include voluntary assisted dying).

The Board recognises the importance of conversations around voluntary assisted dying being conducted in person. However, it must be noted that there is potential for a significant impact to be experienced by rural and remote Victorians unable to use telehealth technology to complete appointments.

“The GP was incredibly supportive. However the travel required (an hour each way, plus appointment) was very draining. It highlighted that needing to conduct all assessments in person was an access issue for those in rural areas. The family would like to see the ability for this appointment to be conducted on video-conference.”

— **Contact person**

Carrying out research

The Board receives important information about aspects of care and the process of voluntary assisted dying.

This includes the disease, illness or medical condition of those people who met the requirements of the eligibility criteria, along with demographic information, and other insights.

To further learn from this information, the Board has formed a special interest group of Board members to develop its approach to research in 2020.

Board members

The Board has 13 members who were appointed in June 2018 for a six-year period. Inaugural members represent a wide range of expertise and skills to help perform the functions and duties of the Board.

2018–2024 MEMBERS

CHAIRPERSON

Justice Betty King

Retired Supreme Court Justice

DEPUTY CHAIRPERSON

Charlie Corke

Intensive care specialist

Margaret Bird

Consultant physician in geriatric medicine

Molly Carlile AM

Senior healthcare leader and palliative care expert

John Clements

Consumer and IT consultant

Sally Cockburn

General practitioner (VR) and broadcaster

Mitchell Chipman

Medical oncologist and palliative care physician

Jim Howe

Neurologist

Danielle Ko

Palliative care physician

Margaret O'Connor AM

Emeritus Professor of Nursing

Paula Shelton

Lawyer

Nirasha Parsotam

Medication safety expert

Melissa Yang

Respiratory and sleep physician, consumer

 **Voluntary Assisted
Dying Review Board**

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