

Voluntary Assisted
Dying Review Board

Report of operations

January to June 2021

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

It details:

- activity since 1 January to 30 June 2021 as well as since the commencement of the *Voluntary Assisted Dying Act 2017* (the Act)
- key lessons drawn from case reviews and feedback.

This report contains quotes and feedback from people who have chosen to die from taking the voluntary assisted dying medication, those who were with them when they died, and trained medical practitioners involved in voluntary assisted dying cases. These quotes have been de-identified to protect the privacy of individuals. This content may be upsetting to some. Contact details for support organisations can be found on page 22.

By law, the Board has been required to report to Parliament every six months for the first two years. This is the final six-monthly report. The next report will be submitted by the end of **September 2022** and will cover the reporting period 1 July 2021 to 30 June 2022.

More information

bettersafercare.vic.gov.au/vad

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Foreword

Two years have now passed since Victoria became the first state in Australia to introduce voluntary assisted dying. Since that time, Western Australia has implemented their legislation, South Australia and Tasmania have passed their own legislation, Queensland has introduced their legislation in Parliament and NSW will soon begin parliamentary debate. There is no doubt that Victoria has played an influential role in inspiring law reform across Australia.

This report covers the period from 1 January to 30 June 2021. It includes key information about how and why Victorians are accessing voluntary assisted dying, and their experience of the process.

It includes insights from medical practitioners and contact persons – often family, friends and carers of applicants – about their experience of the program.

Setting the foundations

The Board commenced its duties a full year before the legislation came into effect on 19 June 2019. This ensured necessary systems and processes were in place to provide safe access to eligible, terminally ill applicants who made a choice to access voluntary assisted dying.

Over the past two years, the Board has turned its focus to robust oversight of safeguards, and then to ensure that each and every application was carefully scrutinised for compliance with the legislation.

This role of informing the Parliament and the public that safeguards have been met has been without doubt our most important function, and it is important for Victorians to know the level to which this has been occurring. The Board has retrospectively reviewed every single form submitted by coordinating and consulting medical practitioners involved in supporting an applicant to access voluntary assisted dying. It is an extraordinary volume of work – for both the Board and the 234 medical practitioners trained and registered in Victoria’s secure medical professionals-only online portal.

Since the Board’s commencement in June 2018, it has, among other things:

- developed and continually improved the processes for reviewing each and every application for voluntary assisted dying that has been made in Victoria
- overseen the development of a secure online portal where medical practitioners are required to submit the forms set out in the Act. This has included a recent review, consultation and implementation process to improve the portal experience for all users
- provided four reports to the Victorian Parliament on the progress of implementing the legislation
- commenced the establishment of a research strategy to enable researchers to access the Voluntary Assisted Dying Review Board’s database. This includes appropriate data management and security processes
- identified and actively managed risks related to voluntary assisted dying
- worked with, and advised other jurisdictions, as they began to consider and then implement similar legislation.

Making improvements

Listening to people involved with the program is paramount to voluntary assisted dying’s continuance as a genuine and compassionate end of life option for Victoria’s late-stage terminally ill.

We have actively collected feedback from applicants, contact persons and medical practitioners involved in voluntary assisted dying applications. Their experiences are helping guide our continuous improvement journey. This includes making several simple improvements to the portal that make it easier for coordinating and consulting medical practitioners to use correctly. Other suggestions have been collated and have informed a major upgrade of the portal and recommendations for future review of the Act.

You will see direct quotes of feedback throughout this report, detailing both positive and challenging experiences. We thank everyone for their effort in engaging with us.

A key challenge

As noted in previous reports, there remains a key challenge that both undermines quality of care and lacks compassion. That is the continued lack of access to telehealth for voluntary assisted dying applicants, who continue to have to attend in-person appointments with their coordinating and consulting medical practitioners so that practitioners do not risk breaching the Commonwealth Criminal Code. This continues to create a barrier to access, as you will see detailed in this report. The Board will continue to advocate for Commonwealth legislative reform in the interests of voluntary assisted dying applicants and their families and carers.

Sharing our lessons learned

As other jurisdictions introduce their own versions of similar legislation, it is important that the Board continues to build relationships with our interstate counterparts. This will help ensure the creation of a minimum dataset, by which we can all share and learn from together.

Thank you and farewell

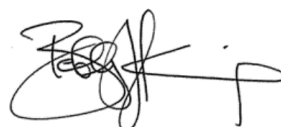
It has been an honour and a privilege to serve as the inaugural chair of the Board – and, by extension, the people of Victoria – for the past three years. I'm very proud that we, as a Board, have been able to support access to this legislation for those who are at the end of their lives and who wish to decide on the manner and timing of their death.

But I feel now is a suitable time for my departure as the program moves beyond establishment. As such, this will be my last report as Chair of the Board.

I would like to thank all the people with whom I worked, including the other 12 Board Members, the Secretary and the Minister. I'd further like to thank the secretariat team which supports all of our functions and the other key teams within the Department of Health who work very hard every day to make sure Victorians have the right to choose voluntary assisted dying. All have been great contributors to the first two years of the program, which has been truly ground-breaking and impactful for many.

Thank you as always to all the health practitioners, statewide services, contact persons, family members and loved ones for your care and support of voluntary assisted dying applicants.

I have no doubt that we will continue to see an increase in the number of Victorians who consider voluntary assisted dying among their options for end of life care. I am proud to have been a part of ensuring that this option is accessible and safe.



Betty King
Chairperson
Voluntary Assisted Dying Review Board

Snapshot

Table 1: Requests received

| Stage | Status | 1 Jul–31 Dec 2020 | 1 Jan–30 Jun 2021 | Total to date | |
|------------------------------|---|---|----------------------|------------------|-----|
| Eligibility | First assessment | Eligible | 221 | 245 | 807 |
| | | Ineligible | 12 | 10 | 29 |
| | Consulting assessment | Eligible | 186 | 217 | 700 |
| | | Ineligible | 4 | 4 | 12 |
| Permit applications | Self-administration permit | Issued | 149 | 174 | 524 |
| | | Not issued | 12 | 15 | 59 |
| | Practitioner administration permit | Issued | 25 | 18 | 73 |
| | | Not issued | 7 | 2 | 18 |
| Withdrawn | Case withdrawn from portal by the coordinating medical practitioner or upon notification of death of applicant* | 108 | 103 | 342 | |
| Medications dispensed | For self-administration# | 127 | 132 | 413 | |
| Confirmed deaths## | Medication was administered | Medication was self-administered | 80 | 92 | 282 |
| | | Medication was administered by a practitioner | 20 | 9 | 49 |

* The figure for withdrawn cases may include administrative errors, duplicate cases, applicants discontinuing the process or those who died before the process was complete. Any duplicate data for an applicant are removed from the data reported.

Medication is only dispensed directly to applicants who hold a self-administration permit. For those issued with a practitioner administration permit, the medication is dispensed directly to the practitioner. Deaths as a result of medication being dispensed to the practitioner are contained within confirmed deaths.

While the Board receives notifications of applicants' deaths from Births, Deaths and Marriages, there are a number of cases where this does not happen – specifically, if the medical practitioner certifying the death does not identify that the applicant was a voluntary assisted dying permit holder on the Medical Certificate Cause of Death. In these cases, confirmation of the manner of death is obtained from contact people or coordinating medical practitioners when following up any unused medication (if medication was dispensed). If a medical practitioner certifying the death does not identify the applicant as a permit holder, notification of death is received once the death is registered. Any apparent differences between this report and the previous report are due to receiving new notifications of registered deaths.

Medical practitioner involvement

Victoria has a growing community of hard-working and compassionate medical practitioners with experience in voluntary assisted dying. Their feedback is helping guide system improvements that will provide a clearer and better process, while ensuring robust safeguards remain.

Medical practitioners are required to successfully complete the online training program prior to participating in eligibility assessments for voluntary assisted dying. For each applicant, there is a coordinating and a consulting medical practitioner. Among other requirements, one of these medical practitioners must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the applicant being assessed.

Once trained, medical practitioners can register in the secure, online Voluntary Assisted Dying Portal. Here, they submit all forms required for voluntary assisted dying and apply for either a self-administration permit or a practitioner administration permit to prescribe the voluntary assisted dying medication. Importantly, coordinating and consulting medical practitioners can only see their own accounts and details of their applicants in the portal.

The Board acknowledges the significant role of these medical professionals who are involved in the program. Without them, access to this end of life choice would not be possible.

Medical practitioner training

There continues to be growth in the number of medical practitioners registered for the online training program, registered in the portal, and involved in one or more voluntary assisted dying cases across Victoria.

Table 2: Medical practitioner training and involvement

| Stage | Description | 1 Jul–31 Dec 2020 | 1 Jan–30 Jun 2021 | Change (%) |
|-----------------------------|--|-------------------|-------------------|------------|
| Online training | Medical practitioner registered for the online training program | 455 | 511 | 12% ↑ |
| Portal registration | Trained medical practitioner registered in the portal | 210 | 234 | 11% ↑ |
| Active in the portal | Trained medical practitioner involved in one or more cases as either coordinating or consulting medical practitioner | 157 | 185 | 18% ↑ |

Types of medical practitioners involved

Most medical practitioners who are trained and registered in the portal are general practitioners or medical oncologists. There are consistently few medical practitioners from other medical specialties, such as neurologists, especially in regional and rural areas. In this context, the travel required to conduct voluntary assisted dying medical appointments in person can be challenging for applicants, their families and carers, and for coordinating or consulting medical practitioners.

Despite the 18 per cent growth in medical practitioners actively participating over the past six months, the Board continues to encourage more medical practitioners to become involved in voluntary assisted dying.

“I have had two referrals from out of [regional area], one of which I had to decline due to the distance issue.” – Coordinating medical practitioner

Table 3: Number of medical practitioners registered in the portal, by specialty (1 Jan–30 Jun 2021)

| Speciality area [^] | Regional and rural | Metropolitan | Total |
|--------------------------------|--------------------|--------------|-------|
| General practice | 61 | 76 | 137 |
| Medical oncology | 14 | 27 | 41 |
| Neurology | 0 | 11 | 11 |
| General medicine | 3 | 5 | 8 |
| Respiratory and sleep medicine | 0 | 6 | 6 |
| Haematology | 2 | 4 | 6 |
| Palliative medicine | 4 | 1 | 5 |
| Other [#] | 8 | 31 | 39 |

[^] Medical practitioners' specialty areas are reported in accordance with the Australian Health Practitioner Regulation Agency (Ahpra) listings. As a medical practitioner may have more than one specialty area listed with Ahpra, the total numbers included in this table exceeds the number of trained medical practitioners registered in the portal.

[#] Other specialty areas include acupuncture, anaesthesia, cardiology, clinical genetics, clinical pharmacology, endocrinology, gastroenterology, general paediatrics, general surgery, geriatric medicine, gynaecological oncology, hepatology, infectious diseases, intensive care medicine, nephrology, neurosurgery, pain medicine, psychiatry, radiation oncology, rehabilitation medicine, rheumatology, sexual health medicine and urology, or do not have a specialty area(s) listed with Ahpra.

Community of practice

The community of practice is an online peer support network that has 37 members. It is a valuable resource for medical practitioners participating in voluntary assisted dying.

Medical practitioners can join the community of practice after successful completion of the voluntary assisted dying training. Those wishing to join should contact vadcommunity@westvicphn.com.au

Medical practitioner feedback

Medical professionals actively involved in the program have provided a range of insights over this latest six-month reporting period. Some key challenges identified include:

- the time and effort involved for coordinating and consulting medical practitioners in each application, particularly for rural and regional practitioners who may be managing multiple applications across large geographic areas
- difficulties with the portal being too complex, with limited guidance about application requirements under the Act included in the workflow
- restrictions of the use of telecommunications (including telehealth) due to the Commonwealth Criminal Code.

Medical practitioner recognition

The Board seeks and receives feedback about the voluntary assisted dying process from contact persons appointed by applicants. Contact people continue to be grateful for coordinating and consulting medical professionals' dedication and compassion.

"The Dr was amazing. Mum had never been one to open up emotionally, but we couldn't believe how open psychologically she was. They really built a special relationship, we all did." – Contact person

"We have some beautiful people working in our medical system and fortunately... I encountered heaps of them." – Contact person

Improving the portal

The Board is appreciative of the feedback provided by coordinating and consulting medical practitioners and other stakeholders about the portal, during engagement sessions held in early 2021.

Work has started on a series of improvements to help make the secure portal easier for coordinating and consulting medical professionals to use, while increasing its analytics and reporting capabilities.

Key enhancements include the development of:

- a streamlined process for transferring practitioners within an application
- easier ways to amend permit application details
- prompts that remind coordinating and consulting medical practitioners about requirements of the Act as they move through the application process
- pre-filled fields across the submitted forms to decrease time and reduce human error in assessment forms.

This work is expected to be completed by the end of September 2021 and some early enhancements have already been implemented in June 2021. Information and training on changes made to the portal will be provided to registered users in due course.

Statewide services

The Victorian Government established two services to support those accessing voluntary assisted dying – the Statewide Care Navigator Service and the Statewide Pharmacy Service. Both services have grown in response to demand since the Act commenced, to accommodate the needs of Victorians and to aid accessibility for applicants – particularly those in regional and rural areas.

Statewide Care Navigator Service

This statewide service provides important advice and support to Victorians who need information about, or assistance with the voluntary assisted dying process.

It has been two years since the service commenced and there are now eight care navigators located across Victoria.

While many people will be well supported through the voluntary assisted dying process by their coordinating medical practitioner, their usual healthcare team or health service, some may need extra support. In these cases, voluntary assisted dying care navigators can work closely with the applicant, their carers, family or friends, medical practitioners, and healthcare teams to make sure the applicant gets the support they need.

Care navigators can also help Victorians to find a voluntary assisted dying trained medical practitioner if their usual general practitioner or specialist medical practitioner is unable to assist them.

From 1 January to 30 June 2021, there were 539 contacts made to care navigators seeking information or support. Of these:

- 36 per cent were from applicants
- 35 per cent were from a family member or friend
- 28 per cent were from medical professionals
- one per cent was from other sources.

“In terms of requesting voluntary assisted dying, the Care Navigator Service was wonderful, and it was easy to find the two practitioners with their help.” – Contact person

Just over half (52 per cent) the people contacting the service are from metropolitan Melbourne.

Of contacts made from 1 January to 30 June 2021:

- 48 per cent were for support for applicants who were planning or were in the process of applying for voluntary assisted dying
- 38 per cent were requests for information from those who were considering voluntary assisted dying
- seven per cent were for assistance in finding a second trained medical practitioner to complete the applicant’s eligibility assessment
- seven per cent were for other reasons.

Contact people and medical professionals have consistently provided positive feedback about the Care Navigator Service during this reporting period.

“Well supported by the Care Navigators as always. They continue to be such an important part of the VAD process.” – Medical practitioner

Not all applicants or medical practitioners are aware of the Care Navigator Service. The Care Navigator Service can be contacted from anywhere in Victoria on 0436 848 344 or vadcarenavigator@petermac.org

"[The applicant] did find some information [about voluntary assisted dying] on the internet, but it was not clear who to speak to initially. The applicant's GP was not sure of the process or contacts either. Eventually it was a nurse who helped find the contact numbers." – Contact person

Statewide Pharmacy Service

The program's Statewide Pharmacy Service has seven pharmacists and one administrative support professional based at Alfred Health in Melbourne.

The Department of Health Secretary (or their delegate) has the power to grant a voluntary assisted dying permit once all required application steps are complete in the portal. After this occurs, it is the applicant's choice to decide if, and when, they want access to the voluntary assisted dying medication.

The pharmacists are responsible for dispensing the voluntary assisted dying medication to applicants who seek access. They are also responsible for the disposal of any unused medication returned by the appointed contact person or medical practitioners.

The pharmacists travel throughout Victoria to provide education and dispense the medication to each applicant at the time of their choosing.

"The pharmacy service was brilliant. They visited on a Sunday. The whole process was smooth and straightforward, and they provided lots of clear information." – Contact person

Dispensing medications

Between 1 January and 30 June 2021:

- 79 per cent of applicants had the medication provided on the day they requested
- more than 99 per cent of applicants had the medication provided within two business days of their preferred day of delivery
- 61 per cent of medications were dispensed to metropolitan applicants
- 39 per cent of medications were dispensed to regional applicants.

"Two pharmacists were lovely and so helpful. They came at a time that suited us. They were thorough, caring and respectful." – Contact person

Feedback from applicants

To continually evaluate and monitor their performance, the service seeks feedback from applicants once they have received their medication.

Between 1 January and 30 June 2021, 47 per cent of applicants provided feedback. Of these:

- 99 per cent reported excellent service from the pharmacist
- 94 per cent said the pharmacist visited at a time that suited them.

"I applied to be a pharmacist in the Statewide Pharmacy Service when the service was first created. End of life care has always been a strong passion of mine, well before I became a pharmacist. I am proud to have been a creator and developer of this service. It is a privilege to visit patients across the state of Victoria in their homes and spend time with them to provide all the necessary information and answer all their questions. I am so grateful to be able to serve people in this unique, Australian-first, way." – Voluntary assisted dying pharmacist

About those seeking and accessing voluntary assisted dying

People who apply for voluntary assisted dying live right across Victoria and span a range of ages. Many express gratitude at having an end of life choice during the late stages of terminal illness.

Applicant details

A total of 900 applicants were registered within the voluntary assisted dying portal as of 30 June 2021. Of these, 93 per cent have had an eligibility assessment completed and submitted to the portal by a coordinating medical practitioner.

Applicants registered in the portal range from 18 to 101 years old, with an average age of 72. This is consistent with the previous reporting period, where the average age was 71. Most applicants are male (54 per cent), born in Australia (70 per cent) and are not of Aboriginal or Torres Strait Islander origin (98 per cent).

The majority speak English at home (95 per cent), do not require an interpreter (98 per cent) and live in a private residence (86 per cent) in metropolitan Victoria (64 per cent). There is little change compared with the previous reporting period.

For the first time, the Board has shared information about the educational level of applicants registered in the portal. This shows that they come from a range of educational backgrounds, with most receiving senior secondary education (24 per cent) followed by junior secondary education (24 per cent).

Table 4: Characteristics of individuals registered in the portal (19 Jun 2019–30 Jun 2021)

| Characteristics | Total (n=900) | % |
|-------------------------|---------------|----------|
| Sex | | |
| Male | 482 | 53.6% |
| Female | 417 | 46.3% |
| Self-described | 1 | 0.1% |
| Age | | |
| 18–54 | 68 | 7.6% |
| 55–64 | 166 | 18.4% |
| 65–74 | 278 | 30.9% |
| 75–84 | 256 | 28.4% |
| 85+ | 132 | 14.7% |
| Median years (range) | 73 | (18-101) |
| Background | | |
| Country of birth | | |
| Australia | 624 | 69.3% |

| Characteristics | Total (n=900) | % |
|---|----------------------|----------|
| Other | 250 | 27.8% |
| Not provided | 26 | 2.9% |
| Aboriginal or Torres Strait Islander | | |
| Yes | 3 | 0.3% |
| No | 878 | 97.6% |
| Unknown | 19 | 2.1% |
| Language spoken at home | | |
| English | 851 | 94.6% |
| Other | 33 | 3.7% |
| Unknown | 16 | 1.8% |
| Interpreter required | | |
| Yes | 19 | 2.1% |
| No | 879 | 97.7% |
| Unknown | 2 | 0.2% |
| Education level | | |
| Primary education or lower | 42 | 4.7% |
| Junior secondary education | 214 | 23.8% |
| Senior secondary education | 217 | 24.1% |
| Certificate level | 48 | 5.3% |
| Graduate diploma and graduate certificate level | 23 | 2.6% |
| Advanced diploma and diploma level | 60 | 6.7% |
| Bachelor degree level | 138 | 15.3% |
| Post graduate level | 57 | 6.3% |
| Other education | 13 | 1.4% |
| Unknown | 88 | 9.8% |
| Residence | | |
| Metropolitan | 577 | 64.1% |
| Regional/rural | 323 | 35.9% |
| Living situation | | |
| Private household | 775 | 86.1% |
| Long term care or assisted living facility | 87 | 9.7% |
| Health service | 33 | 3.7% |
| Unknown | 5 | 0.6% |

* Duplicate data have been removed.

Figures have been rounded to one decimal place and due to rounding the total figure exceeds 100 per cent.

Application numbers

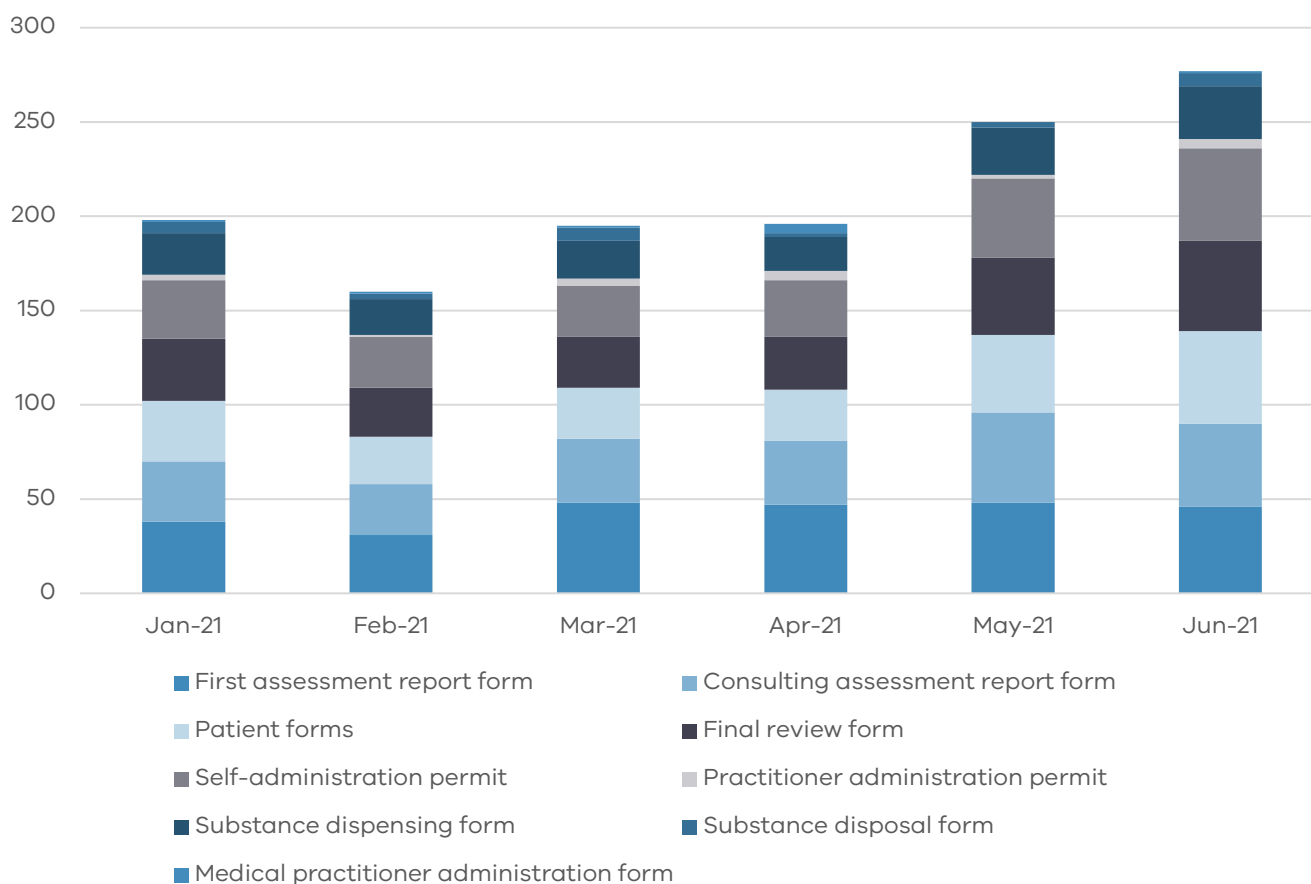
As expected in a program moving from its early stage, activity is growing. Application forms submitted in the portal over the six-month reporting period provide insight into program activity and months of peak demand, in this case, May and June 2021. An average of 213 forms were processed each month across the six-month period.

When compared to the previous six months, from 1 January to 30 June 2021, there were nine per cent more people assessed for eligibility to access voluntary assisted dying.

The Act has clear requirements regarding additional assessments in certain circumstances. When compared with total figures for the previous six months, from 1 January to 30 June 2021 there were:

- 47 per cent more referrals made to a specialist for opinion regarding decision-making capacity
- 51 per cent more referrals made for a specialist neurodegenerative assessment where prognosis was likely to be six to 12 months.

Figure 1: Forms submitted via the portal (1 Jan–30 Jun 2021)



Application timeframes

The Board has highlighted previously that the voluntary assisted dying application process takes time and recommends, where possible, to start the process early. Application process timeframes over the past six months are consistent with previous reports.

"We received turnaround of forms/submissions in a timely fashion. The patient felt 'relieved' that the process was underway and moving along." – Medical practitioner

For all voluntary assisted dying applications where a final request was made:

- 25 per cent were progressed between the first and final request within 11 days
- 50 per cent progressed within 17 days.

"I feel like the process was too long. For someone in my condition, with terminal cancer and incontinence, 10 days is too long." – Applicant

The permit process

Once a coordinating medical practitioner completes the rigorous assessment required by the Act and has submitted the legislated forms in the portal, they can apply for a voluntary assisted dying permit for the applicant.

The Secretary of the Department of Health (or their delegate) is then responsible for deciding whether to issue the permit or not, based on a thorough review of the application material submitted.

Eligibility remains paramount for issuing a permit. In addition to having late-stage terminal illness that will soon cause death, the applicant must provide evidence they are an Australian citizen or permanent resident who is at least 18 years old and have lived in Victoria for a minimum of 12 months.

Once the application materials are submitted and complete, the Secretary (or their delegate) has three business days to determine whether a voluntary assisted dying permit will be issued.

Between 1 January and 30 June 2021:

- 95 per cent of permit outcomes were determined within two business days
- more than 99 per cent were determined within three business days.

There was one application for which the Secretary requested further information/documentation from the applicant, before the permit was issued within four business days.

"The process was huge to get through and is bogged down in bureaucracy. The pathways need to be well defined, and the system needs to be smoother to reduce the hiccups along the way." – Contact person

Errors on the forms can delay the application process and impact on the turnaround time of the permit application.

Common errors include:

- inadequate evidence of eligibility
- incorrect dates for completion of forms
- incorrect spelling of applicant name, address, incorrect/inconsistent date of birth
- incorrect spelling of contact person name
- incorrect medication, incorrect spelling of the medications, incorrect dose or missing route of administration
- missing referrals to specialists in cases where there is a neurodegenerative diagnosis and prognosis between six to 12 months.

Applicants are encouraged to check in with their coordinating medical practitioner regarding the progress of their application.

Coordinating and consulting medical practitioners are encouraged to be careful in correctly filling out the forms and permit application.

Coordinating medical practitioners have provided the Board with helpful feedback on ways permit application errors can be reduced in the portal. This feedback has informed portal enhancements that are under development.

“I would have expected quicker turn around for permit. The application was already reviewed and there was a single error in medication name which was promptly changed.” – Medical practitioner

Permit numbers

When compared to the previous six months, between 1 January and 30 June 2021, there were:

- 209 permit applications received – up eight per cent
- 192 permits issued – up 10 per cent
- 17 permits not issued – down 12 per cent.

Of the 1 January to 30 June 2021 permits not issued:

- 15 were for administrative errors related to the medications, dosages or formulations. All of these were corrected, resubmitted and subsequently approved
- two were due to apparent non-compliance with the Act. One of these applications was subsequently resubmitted and approved and one case was withdrawn.

Most permits issued are for self-administration of the medication, as opposed to coordinating medical practitioner administration.

Deaths

Since the Act was introduced, there have been 488 deaths recorded of voluntary assisted dying permit holders.

Of the voluntary assisted dying permit holders who have died:

- 58 per cent died through self-administration of a voluntary assisted dying medication
- 10 per cent died by administration of a voluntary assisted dying medication by the coordinating medical practitioner
- 32 per cent died without the administration of a voluntary assisted dying medication.

These figures are comparable with those previously reported.

Upon a death, a medical practitioner (any medical practitioner who knows the applicant’s medical history) needs to complete a Medical Certificate of Cause of Death. This must be completed within 48 hours of death.

It is important that medical practitioners completing a Medical Certificate of Cause of Death identify if they reasonably believe the applicant was a voluntary assisted dying permit holder (whether or not they believed the applicant may have taken the medication), so that the Voluntary Assisted Dying Review Board can follow up with the contact person in a timely manner. This is crucial if the applicant has medication that needs to be returned by the contact person to the Statewide Pharmacy Service.

The cause of death will be the applicant’s underlying disease and the manner of death will be recorded as voluntary assisted dying. The extract from the Register of Births, Deaths and Marriages (commonly called a death certificate) will only record the underlying disease and will not state voluntary assisted dying.

At times, a medical practitioner certifying a death may not have been involved in the voluntary assisted dying application and may not know that the applicant was a voluntary assisted dying permit holder. In these circumstances, the Board encourages families and contact persons to help ensure medical practitioners who are certifying the death are aware that a voluntary assisted dying permit was issued to assist in the accurate completion of the Medical Certificate of Cause of Death.

Terminal illnesses

Eligibility for voluntary assisted dying is stringent in accordance with the Act. The diagnosed disease, illness, or medical condition must be incurable; and advanced and progressive; expected to cause the person's death within weeks or months, not exceeding six months, or within 12 months for neurodegenerative diseases. The diagnosed disease, illness or medical condition must be causing the applicant suffering that cannot be relieved in a manner they consider tolerable. It is the diagnosed disease, illness or medical condition that is listed on the applicant's permit to access voluntary assisted dying.

Of all applicants since 19 July 2019 who were issued a voluntary assisted dying permit and have died, 83 per cent had a malignant diagnosis and 17 per cent had a non-malignant diagnosis.

Table 5: Number of applicants issued a voluntary assisted dying permit and have died, by major diagnosis (19 Jun 2019–30 Jun 2021)

| Underlying illness | Total (n=488) | % |
|---|------------------|-------|
| Malignancy | | |
| Primary lung malignancy | 80 | 19.8% |
| Primary breast malignancy | 39 | 9.6% |
| Primary colorectal malignancy | 41 | 10.1% |
| Primary pancreatic malignancy | 41 | 10.1% |
| Other gastrointestinal tract malignancy | 54 | 13.3% |
| Other malignancy | 150 | 37.0% |
| Non-malignancy | | |
| Neurodegenerative disease | 37 | 44.6% |
| Respiratory failure | 18 | 21.7% |
| Other | 28 | 33.7% |

Figures have been rounded to one decimal place and due to rounding the total figure for malignancy is less than 100 per cent.

Withdrawals

The Board receives death information for all applicants, including voluntary assisted dying applications that are withdrawn. An application is considered withdrawn if it does not reach the stage of dispensing of the medication for a self-administration/practitioner administration permit. Between 1 January and 30 June 2021 there were no cases withdrawn because the applicant decided not to proceed.

The main reason for withdrawal was due to death of the applicant before completion of the voluntary assisted dying application process. Data capture has recently been strengthened with the addition of a new reason for withdrawal in the portal, 'The applicant no longer has decision making capacity in relation to voluntary assisted dying'. This data will be included in future reports.

Table 6: Reasons for withdrawal (1 Jan–30 Jun 2021)

| Reason for withdrawal | Total |
|---|-------|
| Coordinating medical practitioner notified of death | 53 |
| Secretariat notified of death [#] | 37 |
| Applicant decided not to proceed | 0 |
| Other [*] | 13 |

[#] The secretariat may receive notification of death via the coordinating medical practitioner, Births, Deaths and Marriages, or a care navigator/care coordinator.

^{*} Other reasons for withdrawal may include an administrative error, deterioration or improvement in condition and thus no longer meeting eligibility criteria and a transfer of care to a different medical practitioner or health service.

Feedback

The Board has the privilege of hearing from applicants and the people who support them.

Importance of voluntary assisted dying

Overwhelmingly, applicants talk about having the choice to decide the timing and manner of their death. It gives them a sense of control at the end of their life, when many other choices are no longer available to them.

“I am losing control of many important bodily functions and do not want that to contribute further to my suffering.” – Applicant

“I have always believed in [voluntary assisted dying]. My body, my brain – my decision. I embrace what I have decided. I’m getting a lot of wonderful healing that I am grateful for.” – Applicant

For some, it is simply having the knowledge that they have the permit or medication available – even though they may choose to never take it. It gives many people great comfort knowing they have a choice to take the medication.

“[The applicant] was so appreciative that VAD was an option for her and it gave her great relief and comfort to know it was there if she wanted it. So, even though in the end she didn’t choose to use it she was so happy to have the choice.” – Contact person

Of all permit holders, 32 per cent died without taking the voluntary assisted dying medication between 1 January and 30 June 2021.

“[The applicant] said my time has come and I’m falling to bits. After that, the process was easy... and well thought through. We had talked about assisted dying extensively. Until we found [voluntary assisted dying], we had talked about going to the Netherlands or Switzerland if the time ever came. We were so lucky to be living in Victoria so we could access it at home.” – Contact person

“The availability of VAD is important because of the choice and control it affords people. Not just to those that use the medication, but anyone who starts the process. The care navigators very regularly receive feedback from family members of people who have died that, just knowing VAD was an option, or that the process was underway, provided great comfort to their loved one.” – Care navigator

Information on voluntary assisted dying

There are resources available to help those interested in learning more about the voluntary assisted dying process and what to talk to their medical practitioner about. Please refer to the [Department of Health website](#).

It has been two years since the legislation was enacted, and community awareness and understanding of voluntary assisted dying is still growing.

“I have believed that dying and death required more open discussion. Now I am in a position of being able to apply to take part in voluntary assisted dying, I appreciate even more the difficulties involved in passing the Victorian state legislation.” – Applicant

“We think that the information needs to be more public so people can have it as choice. It needs to be publicised more. I know it’s a grey area, but it’s not right for all those people who don’t know about it.” – Contact person

Changing from a self-administration permit to a practitioner administration permit

A change in circumstances can occur for applicants holding a self-administration permit causing them to be unable to administer the medication themselves. This may require them to apply for a practitioner administration permit. In these instances, the Act requires any dispensed medication to be returned prior to the coordinating medical practitioner applying for the practitioner administration permit. The process of returning the medication and then applying for and gaining a practitioner administration permit takes time.

Applicants should also be aware that not all voluntary assisted dying trained medical practitioners feel comfortable to administer the medication. This is something an applicant should discuss early with their coordinating medical practitioner.

The Board recommends that coordinating medical practitioners consider their willingness to participate in practitioner administration and any likelihood that the applicant may develop difficulties that may impact their ability to self-administer the medication (for example, swallowing difficulties).

“48 hours to change over a permit from self-administration to practitioner administration when there is no medication to collect or script to destroy needs serious attention. This happens because there is a sudden change in the patient's trajectory and clinical situation.” – Coordinating medical practitioner

Death and support for families

Death can be a confronting experience for families, friends, carers and health practitioners. The Board encourages people to seek support from grief and bereavement services should they need it.

Details for services that may help have been included on page 22.

“I think it would be really helpful for some counselling to be provided to the family regarding what to expect when the patient is dying.” – Contact person

“We called the oncologist when [the applicant] was ready and she was admitted to the hospital under palliative care. She was given a lovely single room with a comfortable recliner to take the medicine. The oncologist drove a long way to be with us. As [the applicant] took the medication, she bought with her some beautiful classical music to listen to. It was a wonderful process and I got to hug her the whole way through until she died. I spent another hour on my own with her after she died. Because we had the substance for a few months, we were both very comfortable with the decision and it was easy to do.” – Contact person

About end of life care and options

Voluntary assisted dying is part of a whole of end of life care perspective. The Board remains committed to ensuring terminally ill Victorians are informed about all their end of life care choices, including advance care planning, palliative care and voluntary assisted dying.

Palliative care involvement

Palliative care services are available to all Victorians and vary depending on the person's care needs. This may include hospital-based care or care delivered in the person's home or residential facility. In some instances, palliative care may be provided by a specialist palliative care provider or specialist consult service.

This is the first time the Board has published data specific to applicants who are receiving care and support from a palliative care service.

It demonstrates that most applicants applying for voluntary assisted dying are currently accessing palliative care services while completing the voluntary assisted dying application process. Palliative care is an essential service available to all Victorians and the Board is pleased to see the integration between these end of life care options and the positive attitudes of voluntary assisted dying applicants about their palliative care experiences.

Table 7: Use of palliative care by VAD applicants (19 Jun 2019–30 Jun 2021)

| Palliative care services | Total (n=900) | % |
|--------------------------|---------------|---------------|
| Accessed | | |
| Yes, currently | 740 | 82.2% |
| Yes, previously | 14 | 1.6% |
| No | 122 | 13.6% |
| Unknown | 24 | 2.7% |
| Duration | | |
| Less than 12 months | 618 | 68.7% |
| Greater than 12 months | 69 | 7.7% |
| Unknown | 213 | 23.7% |
| Median months (range)* | 3 months | (0-72 months) |

Figures have been rounded to one decimal place and due to rounding the total figure exceeds 100 per cent.

* Missing values are not included in the calculation of the median.

“Mum received the most amazing care from the palliative care team. They had already had four people access VAD, so they knew everything about how to help us. The nurse said to us, the more she saw of VAD, the more convinced she was of everyone being able to access it.” – Contact person

About conscientious objection

The Act allows for conscientious objection for registered health professionals who do not wish to participate in voluntary assisted dying.

There are several pathways available to health services and health professionals who decline to become involved that still supports the applicant's rights.

The Board expects that Victorian health services and health professionals will facilitate an applicant's access to information and support, and that conscientious objection will not obstruct or delay the process. Where a health service's values (or those of a particular department within a health service) conflict with voluntary assisted dying, the Board expects the service to utilise policies and procedures for handling applicant information requests.

Some applicants have reported to the Board that they have had difficulty accessing voluntary assisted dying where conscientious objection has been a factor. If health practitioners do not wish to be involved in supporting an individual's request to access voluntary assisted dying, the Board encourages them to refer the individual to the Statewide Care Navigator Service on 0436 848 344 or vadcarenavigator@petermac.org. Inhibiting access to VAD is unlawful in Victoria.

"The applicant had to 'fight hard' at the hospital to access VAD and this was upsetting for her and the family." – Contact person

Individuals seeking information or access to voluntary assisted dying can also contact the Statewide Care Navigator Service directly.

"Her own specialist is a conscientious objector but made the referral himself." – Contact person

Commonwealth Criminal Code

Telehealth is an accepted form of accessing medical care. However, because of the Commonwealth Criminal Code, telehealth is not available to Victorians wishing to access voluntary assisted dying. The Board continues to urge the Commonwealth to consider an exemption approach and acknowledges the barrier the current situation presents to applicants and coordinating and consulting medical practitioners.

Inability to access telehealth remains

As stated in the previous Board report, the ongoing pandemic has highlighted the success of telehealth for healthcare access.

Unfortunately, due to 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*, there is a risk of breaching the Commonwealth Criminal Code to medical practitioners if voluntary assisted dying assessments are conducted via a carriage service (such as telephone or telehealth). This was already a complicating factor for the medical community, but even more so as the pandemic continues.

“This needs to be addressed as a matter of urgency so that the unedifying spectacle of dying people commuting up and down the Hume can be avoided.” – Medical practitioner

The Board continues to urge the Commonwealth to consider an exemption for those accessing voluntary assisted dying, and for it to be treated in the manner of other telehealth consultation options.

Both contact persons and coordinating and consulting medical practitioners have provided feedback to the Board about the added hardship this is causing for applicants.

“The difficulty in physically accessing a consulting practitioner meant that in his dying days, the unfortunate gentleman was required to make a trip to Melbourne (5-6 hours each way) to see a specialist. This is unfair and undignified. I understand and support the need for a consulting practitioner's opinion, but the ban on the use of telehealth creates an unfair and onerous burden for rural and remote patients.” – Medical practitioner

Compliance reviews

The Board retrospectively reviews cases at monthly meetings and determines compliance with the Act for all cases where a permit has been issued and medication dispensed. The Board also reviews potential barriers and seeks to identify improvement opportunities.

Case compliance

In the six months to 30 June 2021, the Board found one case to be non-compliant with the Act.

It is a requirement of the Act that at least one of the coordinating or consulting medical practitioners have practised for at least five years after completing fellowship with a specialist medical college or vocational registration.

In the case deemed non-compliant with the Act, the Board confirmed an error on the part of the coordinating medical practitioner, who believed the consulting medical practitioner met the five-year requirement.

The Board was satisfied that the applicant was eligible to access voluntary assisted dying and met all the eligibility criteria.

The case is being used to inform improvement, with additional measures and protections added to the portal and processes to support medical practitioners to avoid this error and ensure that at least one of the medical practitioners meets this requirement.

From 1 January to 30 June 2021, 99 per cent of applications have been compliant.

Referral to other agencies

During this reporting period, no deaths were considered reportable to the State Coroner. There were no referrals made to the Chief Commissioner of Police or Ahpra.

Key contacts

Safer Care Victoria secretariat

VADboard@safercare.vic.gov.au

Statewide Care Navigator Service

vadcarenavigator@petermac.org

Statewide Pharmacy Service

statewidepharmacy@alfred.org.au

End of life care team, Department of Health

EndofLifecare@health.vic.gov.au

Join a community of practice

For healthcare professionals who support people to access voluntary assisted dying

vadcarenavigator@petermac.org

For medical practitioners who have completed the voluntary assisted dying training

vadcommunity@westvicphn.com.au

Grief and bereavement services

Lifeline (Tel. 13 11 14) provides telephone or online support and counselling 24 hours a day, 7 days a week.

Australian Centre for Grief and Bereavement (Tel. 1800 642 066) provides a statewide specialist bereavement service (including counselling and support groups) for individuals, children and families.

Beyond Blue (Tel. 1300 224 636) provides support 24 hours a day, 7 days a week, with options including telephone, online, email and forums.

Palliative Care Victoria (www.pallcarevic.asn.au) provides information and resources about grief and loss, including details for grief and bereavement services.

Glossary

Applicant

A person wishing to make a request to access voluntary assisted dying. To be eligible they must:

- be aged 18 years or older
- be an Australian citizen or permanent resident
- be ordinarily a resident in Victoria
- at time of request, have been ordinarily a resident in Victoria for at least 12 months
- have decision-making capacity in relation to voluntary assisted dying
- be diagnosed with a disease, illness or medical condition that is incurable, advanced and progressive and:
 - is expected to cause death within weeks or months, not exceeding six months (or 12 months for a neurodegenerative condition)
 - is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.

Contact person

A person appointed under section 39 of the Act. An applicant must, after making a final request, appoint a person who is aged 18 years or older as the contact person. The contact person must return to a pharmacist at the dispensing pharmacy any unused or remaining voluntary assisted dying substance dispensed to the person making the final request either:

- if the applicant dies and the contact person knows that any voluntary assisted dying substance is unused or remaining after the death, within 15 days after the date of death, or
- if the applicant decides to make a request under section 53 for practitioner administration or decides not to self-administer, at the applicant's request.

The contact person will be contacted by the Board to provide feedback and confirm any unused substance has been returned.

Coordinating medical practitioner

A registered medical practitioner who accepts the applicant's first request. Each coordinating medical practitioner and consulting medical practitioner must:

- hold a fellowship with a specialist medical college, or
- be a vocationally registered general practitioner.

Either the coordinating medical practitioner or consulting medical practitioner must have practised as a registered medical practitioner for at least five years after completing a fellowship with a specialist medical college or vocational registration (as the case requires).

Either the coordinating medical practitioner or each consulting medical practitioner must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the applicant being assessed.

Consulting medical practitioner

A registered medical practitioner who accepts a referral to conduct a consulting assessment of the applicant.

