

# Report of operations

## January–June 2020

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

It details:

- activity since 1 January 2020 to 30 June 2020 as well as since the commencement of the *Voluntary Assisted Dying Act 2017*
- key lessons 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 **February 2021** and will cover the reporting period 1 July 2020 to 31 December 2020.

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

This report contains quotes and feedback from people who have chosen an assisted death, and those who were with them when they died. This content may be upsetting to some.

These quotes have been de-identified to protect the privacy of individuals.

### More information

[bettersafercare.vic.gov.au/vad](https://bettersafercare.vic.gov.au/vad)

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# Foreword

Feedback and information gathered over the past six months continue to highlight the compassion and relief Victoria's voluntary assisted dying scheme is providing to terminally ill people, their friends and family. The Board continues to be humbled and honoured to be part of this, as we review the cases and read the touching testimonials of applicants and those who are by their side as they die.

This report covers the second six-month period of Victoria's *Voluntary Assisted Dying Act 2017* and shows a steady increase in the number of people requesting access to voluntary assisted dying.

In our last report, the Board presented limited data as the numbers were relatively small and protecting individual privacy is paramount. With more people now accessing voluntary assisted dying, this report contains additional detail about those who are accessing voluntary assisted dying – including why they seek it, how old they are, and the underlying disease or condition causing death. In this report, we have also included important information for all involved in accessing voluntary assisted dying to help educate and improve understanding of the process for others who may consider it as part of their end of life care options.

In summary, this six-month report shows:

- **access to voluntary assisted dying is growing** – eligible applications increased by 50 per cent from the first six months
- **more doctors are on board to help** – the number of medical practitioners trained and registered in the portal increased by 30 per cent from the first six months
- **access issues in regional Victoria are easing** – 38 per cent of applications were from people living in regional Victoria, and 37 per cent of trained and registered medical practitioners are from outside metropolitan Melbourne. However, there is still a need for more specialists in regional areas
- **compliance with the Act remains high** – one application was deemed non-compliant with the law. This was due to an issue in the paperwork; it was not related to the eligibility of the applicant.

## Using telehealth

Over recent months, many clinicians and health services were able to use telehealth to deliver care and consultation during the coronavirus (COVID-19) pandemic. Unfortunately, due to potentially conflicting Commonwealth legislation (*Commonwealth Criminal Code 1995*), telehealth is not an option for people wishing to access voluntary assisted dying.

With the ongoing requirement for face-to-face consultation in this process, the Board has received feedback that the current COVID-19 pandemic has created additional stress for people who are vulnerable and trying to self-isolate. This has a significant impact on Victorians living in regional areas or for those who find it incredibly difficult to travel due to their clinical condition.

This Board is repeating its call for the Commonwealth to reconsider making an exemption from the Criminal Code to allow Victorians, especially those in regional Victoria, to be able to have important conversations about voluntary assisted dying over the phone or via teleconference.

## Feedback is helping to improve the process

As part of the application process, applicants have the option of providing a personal statement. The statements received were very clear that voluntary assisted dying is about their personal choice, having control, and maintaining dignity in their death.

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However, a number of people expressed concern about a lack of support by doctors or health services opposed to voluntary assisted dying. We remind doctors there is a way to decline support, without causing additional distress to the applicant and their family.

**“Unfortunately, the long-standing GP was not supportive of the request for voluntary assisted dying and he felt he could no longer consult with his GP.” – Contact person**

Many people – including some family members who were initially opposed to voluntary assisted dying – expressed gratitude that they were able to say goodbye to their loved ones.

**“It was a beautiful, peaceful death. Was absolutely a pleasant and calm process which gave me so much relief to see her go so serenely.” – Contact person**

In this report, we have highlighted important lessons for applicants and medical practitioners to help in the process of applying for a permit and to establish expectations on timelines. While most applications take a few weeks, we continue to see a small proportion of applications delayed by minor inconsistencies or errors, and omissions of information that require follow up. This can be frustrating for all, especially if the applicant’s health is deteriorating.

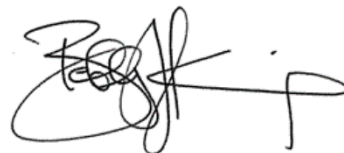
This year, we started seeking formal feedback from the medical practitioners who support applicants through the process. A few doctors told us that the process is complex and time consuming. But voluntary assisted dying is not an emergency procedure. It takes careful planning and time. While we support the 68 safeguards contained in the Act to ensure its safe operation, we do listen to this feedback and continue to improve the portal to make the process of applying easier wherever possible.

The Board continues to welcome feedback and suggestions for improvement to aid the safe operation of voluntary assisted dying in Victoria. Please email [VADboard@safecare.vic.gov.au](mailto:VADboard@safecare.vic.gov.au)

## 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 continue to give 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.



**Betty King**  
Chairperson  
Voluntary Assisted Dying Review Board

# Snapshot

**Table 1: Requests received from 1 January 2020 to 30 June 2020 and since 19 June 2019**

STAGE		STATUS	SUBTOTAL (19 June– 31 December 2019)	SUBTOTAL (1 January– 30 June 2020)	TOTAL <sup>^</sup> (19 June 2019– 30 June 2020)
<b>Eligibility</b>	First assessment	Eligible	136	205	<b>341</b>
		Ineligible	1	6	<b>7</b>
	Consulting assessment	Eligible	109	188	<b>297</b>
		Ineligible	3	1	<b>4</b>
<b>Permit applications</b>	Self-administration permit	Issued	75	126	<b>201</b>
		Not issued*	16	16	<b>32</b>
	Practitioner administration permit	Issued	11	19	<b>30</b>
		Not issued*	4	5	<b>9</b>
	Withdrawn	Case withdrawn from portal by medical practitioner or upon notification of death of applicant**	35	99	<b>134</b>
<b>Medications dispensed</b>	For self-administration <sup>#</sup>		57	97	<b>154</b>
<b>Confirmed deaths<sup>##</sup></b>	Medication was administered	Medication was self-administered	37	67	<b>104</b>
		Medication was administered by a practitioner	9	11	<b>20</b>

<sup>^</sup> Any apparent differences between this report and the first report are due to provisional results from the first six months being adjusted after finalisation and confirmation.

\* In the last report, the Board did not report on 'not issued' permits as all permits initially not issued, were re-applied for and subsequently issued. In this report we are providing the data for all permit applications. Any permit not issued on first application was subsequently re-applied for and issued and are reflected in the total permits issued.

\*\* The ability for medical practitioners to withdraw a case in the portal has recently been enhanced and this has been communicated. As a result, there has been an increase in withdrawn cases since the previous report. This figure includes administrative errors, duplicate cases, applicants ceasing to continue the process or those who died before the process was complete. Further detail as to reasons for withdrawal will be provided in future reports.

<sup>#</sup> 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.

<sup>##</sup> While the Board receives notification of death of permit holders from Births, Deaths and Marriages, there are a number of cases where the manner of death is not reported to the Board. This occurs if the medical practitioner certifying the death does not select that the person was a voluntary assisted dying permit holder on the Medical Certificate Cause of Death (MCCD). In these cases, confirmation of the manner of death is obtained from contact persons or coordinating medical practitioners as part of the process of following up any unused medication.

**“It gave him and his family a chance to celebrate his life and die the way he wanted to, when he wanted to.” – Contact person**

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# How the voluntary assisted dying legislation works

Medical practitioners, the Secretary of DHHS, and the Voluntary Assisted Dying Review Board all have important roles and responsibilities defined within Victoria's *Voluntary Assisted Dying Act 2017*. It is important to note the Board is responsible for monitoring and reviewing matters related to voluntary assisted dying but does not have any power to approve or refuse access to voluntary assisted dying.

## Application and assessment checks

Medical practitioners submit the relevant forms and required evidence on behalf of the applicant to the Voluntary Assisted Dying Review Board. This is done via the Voluntary Assisted Dying Portal.

At this point, the secretariat for the Board undertakes an administrative check to ensure sufficient information has been provided. At times, medical practitioners may be asked to clarify or provide more information. This is done to ensure there are no delays when a permit application is made to the Secretary, DHHS.

On completion of the five required forms, the coordinating medical practitioner makes a request for a permit. The request is then considered by the Secretary, DHHS.

## About Safer Care Victoria

Safer Care Victoria provides administrative day-to-day operational support of the portal and the Board secretariat.

## Permit approvals

The power to issue or refuse a voluntary assisted dying permit sits with the Secretary, DHHS or their delegate.

The Secretary must be satisfied that all the pre-conditions in the Act have been met and that the request and assessment process has been completed.

## Compliance review

Once a voluntary assisted dying application is complete, either because the applicant has died or chosen not to continue with the process, the Board rigorously reviews all the forms and information submitted to determine if the case was compliant with the Act.

The secretariat seeks feedback from nominated contact people, medical practitioners and other agencies that support the voluntary assisted dying process. This is to assist the Board with its numerous responsibilities, including the individual application review process, education, research and future improvements.

## About the Board

Appointed in July 2018, the Board retrospectively reviews all cases of voluntary assisted dying for compliance with the Act. The Board does not approve, refuse or reject assessments and applications.

For Board membership, see page 18.

More detail on the Board's role and functions is available at [bettersafercare.vic.gov.au/vad](https://bettersafercare.vic.gov.au/vad)

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# Application and assessment

To help people make informed choices and submit complete applications, Victorian agencies work together to support community members and medical practitioners in understanding the legislation and its requirements. Over the past year, the number of medical practitioners trained to make applications on behalf of applicants has grown, and support services for members of the community and medical practitioners have expanded their reach to meet requests.

## COMMUNITY INFORMATION AND SUPPORT

Since the commencement of the Act, the **Statewide Voluntary Assisted Dying Care Navigator Service** has provided support to 613 people seeking information about voluntary assisted dying.

Community members, medical practitioners and health services can request:

- general information about voluntary assisted dying in Victoria
- individualised support and information, either in a face-to-face consultation or by post
- help in connecting people with appropriate medical practitioners and health services
- access to voluntary assisted dying support packages
- holistic advice and follow up on appropriate end of life care services
- education for health services and health practitioners.

*“I can no longer partake in the small joys that fill the day; chatting, playing with my cats, walking, jogging, eating wholeheartedly.”*

– Applicant

In early 2020, the service was expanded to include additional care navigators across regional Victoria in order to provide consistent support to individuals and clinicians, regardless of their location. This was in response to feedback received in the first six months of the legislation.

In the first three months of the regional expansion (March to June), the regional care navigators provided support to 84 people seeking information about voluntary assisted dying.

More than 35 health professionals, who have roles related to voluntary assisted dying, have joined a community of practice to share experiences, lessons and support between participants.

*“Initially we could not find any doctors willing to help or who were trained. Then we were able to access the care navigators and once they were involved, they made it much easier.”* – Contact person

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## Important lessons for the community

### Increased awareness and community conversations

The conversation around voluntary assisted dying is continuing to expand and more Victorians are becoming aware of the options available to them.

- Applicants must have an incurable and advanced disease, illness or medical condition that is expected to cause death within six months (or 12 months for a neurodegenerative condition). However, voluntary assisted dying is not just for people with cancer or neurodegenerative conditions. Voluntary assisted dying is applicable for any illness or disease that may be terminal.
- While the Act outlines the minimum required information related to diagnosis and prognosis, the Board encourages medical practitioners to provide adequate supporting clinical documentation as this information is incredibly useful in understanding the reasons people are requesting voluntary assisted dying.
- Some applicants may be assessed by a medical practitioner as ineligible. In this circumstance, the applicant can be assessed by the same medical practitioner at a later time or may wish to seek an opinion and assessment from a different medical practitioner.
- People are encouraged to talk to their family and doctor about their end of life preferences. Registered health practitioners are not able to initiate a discussion about voluntary assisted dying.
- Voluntary assisted dying does not appear on someone's death certificate. The underlying disease or illness is recorded as the cause of death.
- Some applicants may require an interpreter, so planning and timely access is important.

### Demonstrating evidence of Australian citizenship or permanent residency

- Some people may have lived in Australia for 40 years or more and never become an Australian citizen or permanent resident.
- You can be on the Australian electoral roll or receive Commonwealth services without being a citizen or permanent resident.
- An email or print-out of a person's permanent visa status, as recorded in the Visa Entitlement Verification Online (VEVO) system operated by the Department of Home Affairs is sufficient evidence.
- If a person arrived in Australia before 1990 and has not travelled overseas since, they may not have a VEVO record. In that case, the person needs to apply for an electronic visa record. Processing times and further information can be found at [immi.homeaffairs.gov.au/visas/permanent-resident/evidence-of-residency-status](https://immi.homeaffairs.gov.au/visas/permanent-resident/evidence-of-residency-status)



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## MEDICAL PRACTITIONER TRAINING AND SUPPORT

Increasing by 15 per cent from the first six months, 422 medical practitioners have now registered for the mandatory voluntary assisted dying training in order to support applicant requests. Seventy-six per cent of the medical practitioners who completed the medical training are registered users in the portal.

Coordinated by the **DHHS End of Life Care team**, this training helps medical practitioners become familiar with the many safeguards and requirements built into the Act, and what information and evidence needs to be supplied.

Medical practitioners must complete and pass the training before undertaking an assessment as a coordinating or consulting medical practitioner. As training can take some time to complete, and in order to avoid delays, the Board recommends practitioners complete the training in advance of any anticipated need.

“The GP had to finish his training before he could coordinate, and this took a few weeks.

Sourcing the oncology specialist was a bit harder as the first one identified had not done [the] training. The second one recommended by the care navigators saw us almost straight away.” – Contact person



**422** medical practitioners registered for training

**175** registered in the portal

**125** doctors active in the portal

### Of the medical practitioners who have completed the training and are registered in the portal:

- 50 per cent are general practitioners
- 16 per cent specialise in oncology
- five per cent specialise in neurology
- three per cent specialise in palliative medicine.

More than a dozen trained medical practitioners have joined a community of practice to provide support to others going through the training. We would encourage those who have completed the training to join this community of practice to share information and their expertise.

### Location of medical practitioners

Thirty-seven per cent of trained and registered medical practitioners are now located in regional and rural Victoria and 63 per cent are in the metropolitan area.

Some contact people continue to report to the Board that it was difficult to find medical practitioners who have completed the training and are willing to assist.

With time, the number of trained medical practitioners will continue to increase.

“Being a new process, it was hard to find information or know how to find a doctor willing to do voluntary assisted dying. Once established, the process went well. The care navigators assisted with identifying doctors who were willing to see patients to access voluntary assisted dying.” – Contact person

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## THE VOLUNTARY ASSISTED DYING PORTAL

The Voluntary Assisted Dying Portal is the only avenue for forms to be submitted to the Board.

From feedback received by the Board, some medical practitioners find the portal difficult to use.

**“The GP had multiple issues with the portal and told us he found it more than he could handle.” – Contact person**

As a result, some improvements have been made to the way users experience the portal.

Improvements include:

- additional prompts and instructions for medical practitioners
- the ability to record both the date of assessment and date of declaration
- improved recording of an applicant and their nominated contact person’s addresses to reduce errors/discrepancies
- improved functionality and data capture for withdrawn cases
- improved processes for when the coordinating and consulting medical practitioners exchange roles
- exploring the development of training specific to the use of portal.

The Board has recently commenced seeking this feedback in a more formal manner and is also hoping to make further improvements and upgrades to the portal in the next 12 months.

**“It was my first time accessing the system as a medical practitioner and the system seems quite intuitive. I believe I’ll be more efficient on subsequent occasions when accessing the system for future patients.”**  
– Medical practitioner

## VOLUNTARY ASSISTED DYING APPLICATIONS

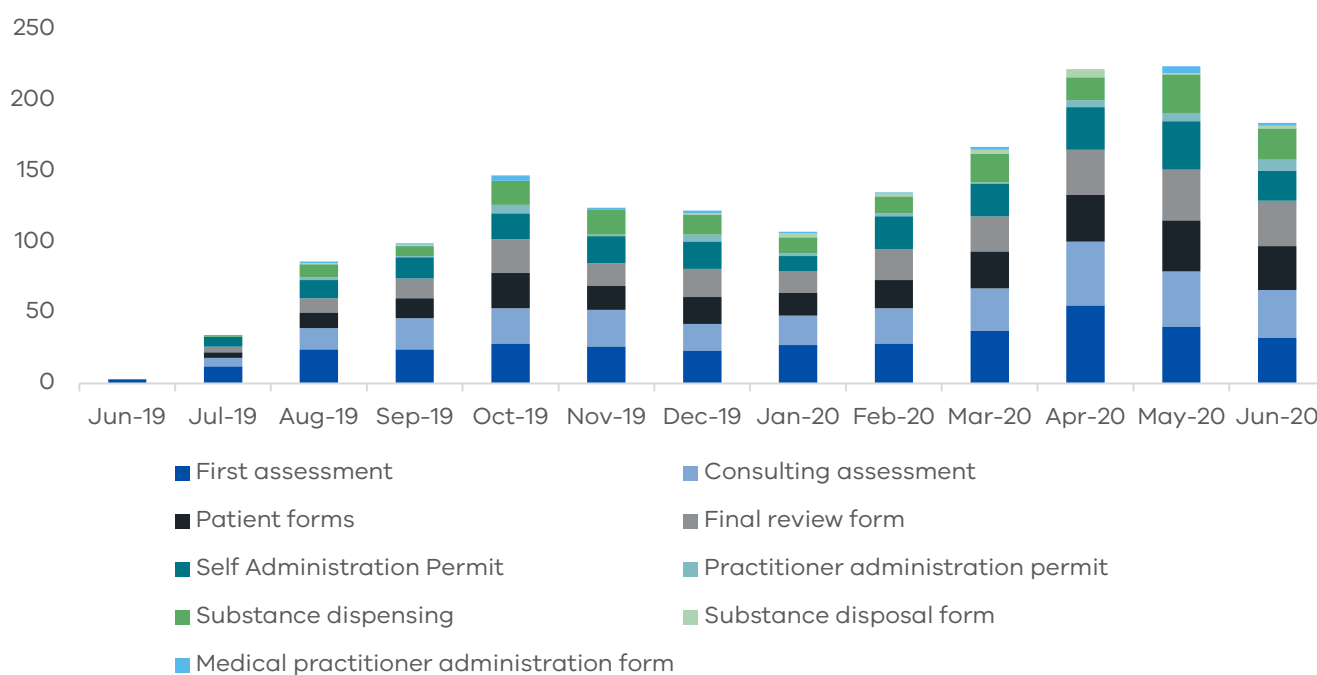
Between 1 January 2020 and 30 June 2020, there were 211 first assessments submitted into the portal and assessed as eligible or ineligible.

With more than 120 people having now died as a result of taking, or being administered, the voluntary assisted dying medication, we are able to share more information about them without the risk of identifying those people or their medical practitioners.

Data showed:

- applicants for voluntary assisted dying were aged between 32 and 100 years, with an average age of 71
- 44 per cent of applicants were female, 55 per cent were male and one per cent selected ‘self-described’
- 62 per cent of applicants resided in a metropolitan area and 38 per cent in a regional or rural area
- 68 per cent of applicants were born in Australia
- the majority of applicants spoke English at home, and nine required an interpreter to attend appointments.

## Forms submitted via the portal



## Reasons for accessing voluntary assisted dying

Loss of autonomy was frequently cited by applicants as a reason for requesting voluntary assisted dying.

**"I wish to die in my own home and wish to have some control over my death. I do not wish to live as a vegetable in my own body. I have a condition for which there is no cure."**

– Applicant

Other reasons for accessing voluntary assisted dying which were commonly reported included being less able to engage in activities that make life enjoyable, losing control of body functions, and loss of dignity.

**"My reason is my brain tumours and I know I will become incapacitated with my motor skills and seizures. I would rather a natural death but it does not seem likely."** – Applicant

## Cause and manner of death

Since the commencement of the Act, the permit holders who died comprised:

- 58 per cent who died through self-administration of a voluntary assisted dying substance
- 11 per cent who died by administration of a voluntary assisted dying substance by a medical practitioner
- 31 per cent who died without the administration of a voluntary assisted dying substance.\*

\* Either before the medication was dispensed or the substance was not taken and subsequently disposed of.

**"She had always planned to have the medication as a plan B should her disease progress past bearable, however she died peacefully and calmly from natural causes in hospital."** – Contact person

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For all applicants who had a permit issued and have subsequently died, 78 per cent had a malignancy diagnosis and 22 per cent had a non-malignant diagnosis.

Of the malignancy group:

- 17 per cent had a primary lung malignancy
- 15 per cent had primary breast malignancy
- 11 per cent had other gastrointestinal tract malignancy
- 10 per cent had primary pancreatic malignancy.

Of the non-malignant group:

- 15 per cent had a neurodegenerative disease
- seven per cent had other diseases such as pulmonary fibrosis, cardiomyopathy or chronic obstructive pulmonary disease.

No deaths were considered reportable to the coroner.

**“A beautiful passing; there were candles and music, he told a joke before taking the medication and followed the medication with a drink of port. It was the way he wanted to go.”**

**– Contact person**

## **TIMELINESS**

The voluntary assisted dying process is a serious matter which takes time and requires thoughtful planning.

Since 19 June 2019, 25 per cent of applicants have progressed between their first and last request within 11 days and 50 per cent within 19 days.

**“The process was new for all involved and there was quite a bit involved with paperwork and checks etc and this took time. But we fully understood the due diligence required and taken and felt all practitioners involved did a great job.” – Contact person**

There are occasions when the person applying for voluntary assisted dying dies before the process is complete. There are several reasons why this might occur. It could be due to delays in finding a medical practitioner to assess the applicant, because it takes time to gather all the necessary evidence, or because the process was started too late in the applicant's life.

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## Important lessons in making an application

### Understanding that applications take time

Voluntary assisted dying is not an emergency medical procedure and it takes time, consideration and thoughtful planning. Medical practitioners should discuss all the requirements of the legislation, the steps in the process and realistic timeframes. This should take into account access to medical practitioners over extended holiday periods such as Christmas/New Year and Easter.

### Make sure the application is complete before submitting

If an applicant has all the required information, the process should only take a few weeks. However, it can take much longer if there are delays in gathering evidence, accessing medical practitioners, and completing the paperwork or correcting errors.

To prevent delays and avoid common errors, please:

- ensure all eligibility evidence is included, specifically the person's prognosis (in addition to their diagnosis) and proof of citizenship or residency
- check you have correctly entered and spelled the person's name, address and date of birth, and the medications being requested in the permit
- submit all forms within mandated periods
- ensure all uploaded documents are legible (if photographed), and are correctly signed and dated, especially the written declaration and contact person appointment forms.

### Likely prognosis and clinical deterioration

For some applicants, the decline in their condition may be more rapid than anticipated. If there is a sudden or rapid deterioration in the applicant's medical condition, consider using section 38(2) of the Act to expedite the application process. This can be applied if both the coordinating and consulting medical practitioners agree the applicant is likely to die within the usual nine-day period between first and final requests.

### Selecting an eligible witness for Form 3

Form 3 is a written declaration by the applicant to confirm they have decision-making capacity, were not coerced, and chose to die in this way. The applicant must sign this form in the presence of two witnesses. Witnesses to the declaration must see and acknowledge that signature and statement. Additionally, the witnesses to this declaration must not knowingly:

- be a beneficiary under a will
- benefit from the death of the applicant (financially or in any other material way)
- be the owner/operations manager of the health facility where the applicant is being treated or lives
- be directly involved in providing professional care services to the applicant.

No more than one witness may be a family member.

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# Permit approvals and medication dispensing

The Secretary, DHHS or their delegate has the power to grant a voluntary assisted dying permit. Once this occurs, it is up to the applicant to decide if and when they want access to the voluntary assisted dying medication.

Between 1 January and 30 June 2020, the Secretary, DHHS issued 145 self-administration or practitioner administration permits.

Twenty-one permit applications were not issued. Of these:

- 20 were not issued due to administrative errors in the prescribing of the medications
- one was not issued because of insufficient evidence of the applicant's eligibility.

All 21 applications were resubmitted and subsequently approved once errors were corrected or further evidence provided.

## TIMELINESS

Once all necessary evidence and forms had been submitted in line with legislative requirements, 68 per cent of permits were issued within two business days.

The Voluntary Assisted Dying Regulations 2018 state the Secretary, DHHS has three business days to determine an application.

## DISPENSING AND MONITORING MEDICATIONS

Once a permit is issued, the **Statewide Pharmacy Service** works with the applicant and their medical practitioner to ensure the relevant medications are provided to the person in a timely manner.

Between 1 January and 30 June 2020:

- 42 per cent of medications were dispensed within two business days of being requested by the applicant
- 68 per cent of medications were dispensed to metropolitan applicants
- 32 per cent of medications were dispensed to regional applicants.

The Statewide Pharmacy Service, based at Alfred Health, provides support and information on the dispensing process. It is the only dispensary for voluntary assisted dying medications in Victoria and operates five days a week during business hours.

The Statewide Pharmacy Service visits applicants anywhere in Victoria. The visit is organised when the applicant contacts the service after a permit has been approved. The visit occurs at a time that suits the applicant and after the coordinating doctor and pharmacist have had a face-to-face meeting.

“The pharmacy team were very thorough and clear in their instructions. It was beautifully done and very respectful of the patient's privacy. They were so kind and understanding.”

– Contact person

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The Board continues to receive extremely positive feedback about the compassionate support provided by the pharmacists. It acknowledges the significant transition the Statewide Pharmacy Service and other frontline services have undergone over the past year as voluntary assisted dying has come into existence and demand has increased.

While it is acknowledged that voluntary assisted dying is not an emergency medical procedure and takes time and thoughtful planning, the Board has observed that accessing voluntary assisted dying can be an anxious process, and that some applicants and contact people felt they had to wait too long to receive their medications.

**“There were no issues once they received the medication; however, it took far too long.”**

**– Contact person**

Dispensing and managing these medications is critical to ensuring that voluntary assisted dying is safely implemented across the state. The service offers a delivery, collection and support service to people accessing voluntary assisted dying and their medical practitioners.

## Important lessons in the permit approval and medication stage

### Support the contact person and loved ones

Supporting someone through the voluntary assisted dying process is a very personal experience. Some contact people report feeling very uplifted by the experience and others find it very confronting. Some have also reported an initial reluctance to play the role of contact person, but on reflection, described it as an honour. Supports available include:

- Australian Centre for Grief and Bereavement: 1800 642 066
- GriefLine: 1300 845 745
- Lifeline: 13 11 14

*“The son lives interstate and was initially in denial of his mother's choice. However, when he came over and saw how sick and in distress she was, he was accepting of her decision, the process, and got on board straight away.” – Contact person*

### Understand voluntary assisted dying is a personal choice

Voluntary assisted dying is a very personal choice and not everyone will be supportive. Some people may experience difficulty at the end of their life if their care providers do not agree with the request. Health practitioners who have a conscientious objection have the right to refuse to participate.

*“The staff provided great clinical care, however were not supportive of voluntary assisted dying, so he had to be moved to another facility. This was very stressful at the time; however, the new facility gave him a private room in the most beautiful setting and were very supportive.” – Contact person*

### Timely approval of permits

To facilitate timely approval of voluntary assisted dying permit applications, medical practitioners are asked to please take note of the following when completing permit applications:

- Double check the spelling of the drug, dose and route of administration.
- Double check the details of the applicant and the contact person are correct, including addresses.

Any missing or incorrect information on the permit application form may result in unnecessary delays and the permit being declined.

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

While self-administration might be appropriate for the applicant initially, it may not always be when close to death. Coordinating medical practitioners can apply for a new practitioner administration permit if the applicant has lost the physical capacity to swallow or digest the medication.

Before an application for a practitioner administration permit can be made, the unfilled prescription must be destroyed, or if the medication has already been dispensed, it will need to be returned to the Statewide Pharmacy Service and disposed of.

*“I was worried she wouldn't be able to swallow the medication.” – Contact person*



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# Compliance 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 and are determining an approach to future research.

## CASE COMPLIANCE

In the six months to June 2020, the Board found one case to be non-compliant with the Act.

The Board found that while the applicant was eligible for a voluntary assisted dying permit, there was a failure to comply with the procedural requirements of the Act by a medical practitioner. The Board referred the matter to the Australian Health Practitioner Regulation Agency (AHPRA).

 **99% cases compliant**

## IMPORTANCE OF COMPLIANCE

The Board has a very low threshold for errors or inconsistencies in applications.

While some may view these errors or inconsistencies as minor or trivial, voluntary assisted dying is a very serious matter. There are 68 safeguards in the Act. These requirements were included by Parliament to ensure voluntary assisted dying is safe. Accordingly, compliance with those requirements must be demonstrated.

## Demonstrating sufficient evidence of Victorian residency

In the past six months, one case was brought to the Victorian Civil and Administrative Tribunal (VCAT) to challenge a determination on an applicant's Victorian residency.

The Act requires that for a person to be eligible for voluntary assisted dying, the person must:

- be ordinarily a resident in Victoria, and
- at the time of making a first request, have been ordinarily a resident in Victoria for at least 12 months.

Medical practitioners report that it is often difficult to demonstrate sufficient evidence to meet this requirement. It is particularly difficult for people who travel around Australia for long periods.

In one case, the secretariat requested additional information from the coordinating medical practitioner to enable the Secretary, DHHS to make an informed decision about a permit application. The coordinating medical practitioner asserted the applicant met the residency criteria and exercised their right to commence a VCAT proceeding to have the assessment reviewed.

During the proceedings, the applicant provided further information. Once this was submitted, VCAT and the Secretary agreed that the applicant met the residency requirements and the case progressed unopposed.

The voluntary assisted dying process is dictated by the requirements of the Act. It is important that anyone wishing to apply for voluntary assisted dying understands what is required in relation to eligibility and collects the relevant information as early as possible.

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## IMPROVEMENTS TO THE VOLUNTARY ASSISTED DYING PROCESS

The Board has a role to promote continuous improvement in the quality and safety of voluntary assisted dying, as well as to provide advice to the Minister for Health or Secretary, DHHS.

The Board uses all the information it receives from case reviews, as well as feedback from contact people and medical practitioners, to consider the advice it may provide in relation to any improvements.

The Minister must also cause a review of the operation of the Act, which will be conducted in the fifth year and review the first four years of operation of the Act.

### Inability to use telehealth

The current COVID-19 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*, it is an offence to use a carriage service (such as telephone or telehealth) for suicide-related material, which may include voluntary assisted dying. This places medical practitioners at risk of prosecution. This was already a complicating factor for the medical community, but even more so during the pandemic.

The Board has received anecdotal feedback about challenges faced by some applicants and families in completing face-to-face assessments while COVID-19 measures have been in place.

The Board remains very concerned about the impact the criminal code may have on Victorians, particularly in rural and remote regions, who are unable to use telehealth technology to complete appointments.

“The process took so long. We started the process six months prior to her death. It was extremely hard travelling to appointments and arranging interpreters. Many times, the interpreters did not show or cancelled at the last minute.” – Contact person

### Feedback on improvements

The Board has received feedback from applicants, contact people and medical practitioners that the following changes may improve the experience of people wishing to apply for voluntary assisted dying:

- Expanding voluntary assisted dying services and supports to be accessible seven days a week.
- Easier access to medical practitioners who have already completed the training, including more specialists (e.g. neurologists).
- Allowing telehealth appointments.
- Continued access to high-quality palliative care services.
- Promoting greater community awareness and conversations about end of life, including voluntary assisted dying.
- Further improvements to the portal to allow for greater efficiencies.
- Ability for medical practitioners to initiate a conversation about voluntary assisted dying (currently constrained by legislation).

“There was a wait time of one month to see the specialist and she had to go to Melbourne with her daughter as there was no specialist involved in the program locally. This was too much. It was a terribly long day and she was in considerable pain. She was exhausted by the end of it.” – Contact person

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## SHARING OUR EXPERIENCE WITH OTHER JURISDICTIONS

The Board has been cooperative when approached by various representatives from Western Australia and Queensland, so that they can learn from and understand the experiences of the Victorian legislation.

## RESEARCH

When information is provided, one of the Board's roles is to conduct analysis of, and carry out research in relation to, this information.

The Board has established a special interest group of Board members and is in the process of developing a strategy for its approach to research.

The Board has received a small number of requests from researchers wishing to access data related to voluntary assisted dying. The Board is very supportive of research being conducted on this topic and intends to share this data once there is sufficient data to protect the privacy of individuals.

## The known unknowns

The Board only has the power to collect, use and disclose information provided to it in accordance with the Act. That means there is a lot of important information related to voluntary assisted dying that the Board does not have the power to obtain. This includes information such as:

- the number of people who are not able to find a trained medical practitioner to assist them
- the number of people who are assessed as ineligible by a medical practitioner (unless the medical practitioner submits an assessment)
- the number of people who are dissuaded by their medical practitioners from seeking voluntary assisted dying
- those in nursing homes or private or public hospitals who are not supported in accessing voluntary assisted dying
- those who are told that if they wish to access voluntary assisted dying, they will have to leave the facility in which they have been residing or are being cared for, such as a nursing home, hospital or palliative care ward or organisation.

The Board recognises that there may be other organisations or entities with access to this type of information. The Board welcomes feedback related to this and would be very supportive of the ability to access linked data and information.

**“While her medical practitioners were very understanding and supportive of her decision, some of the other staff were uncomfortable about it and the hospital was not supportive.”**

**– Contact person**

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# 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**

Specialist general practitioner (VR) and health educator

**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 specialist

**Melissa Yang**

Respiratory and sleep physician, consumer

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# Key contacts

## **Safer Care Victoria secretariat**

[VADboard@safercare.vic.gov.au](mailto:VADboard@safercare.vic.gov.au)

## **Statewide Voluntary Assisted Dying Care Navigator Service**

[vadcarenavigator@petermac.org](mailto:vadcarenavigator@petermac.org)

## **End of life care team, DHHS**

[EndofLifecare@dhhs.vic.gov.au](mailto:EndofLifecare@dhhs.vic.gov.au)

## **Statewide Pharmacy Service**

[statewidepharmacy@alfred.org.au](mailto:statewidepharmacy@alfred.org.au)

## **Join a community of practice**

**For healthcare professionals who support people to access voluntary assisted dying**

Email [vadcarenavigator@petermac.org](mailto:vadcarenavigator@petermac.org)

**For medical practitioners who have completed the voluntary assisted dying training**

Email [vadcommunity@westvicphn.com.au](mailto:vadcommunity@westvicphn.com.au)

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# Glossary

Term	Definition
<b>Applicant</b>	<p>A person wishing to make a request to access voluntary assisted dying.</p> <p>To be eligible they must:</p> <ul style="list-style-type: none"><li>• be aged 18 years or older</li><li>• be an Australian citizen or permanent resident</li><li>• be ordinarily a resident in Victoria</li><li>• at time of request, have been ordinarily a resident in Victoria for at least 12 months</li><li>• have decision-making capacity in relation to voluntary assisted dying</li><li>• be diagnosed with a disease, illness or medical condition that is incurable, advanced and progressive and:<ul style="list-style-type: none"><li>• is expected to cause death within weeks or months, not exceeding six months (or 12 months for a neurodegenerative condition)</li><li>• is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.</li></ul></li></ul>
<b>Contact person</b>	<p>A person appointed under section 39 of the Act.</p> <p>An applicant must, after making a final request, appoint a person who is aged 18 years or older as the contact person.</p> <p>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:</p> <ul style="list-style-type: none"><li>• if the person 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</li><li>• if the person decides to make a request under section 53 for practitioner administration or decides not to self-administer, at the person's request.</li></ul> <p>The contact person will be contacted by the Board to provide feedback and confirm any unused substance has been returned.</p>
<b>Coordinating medical practitioner</b>	<p>A registered medical practitioner who accepts the person's first request.</p> <p>Each coordinating medical practitioner and consulting medical practitioner must:</p> <ul style="list-style-type: none"><li>• hold a fellowship with a specialist medical college, or</li><li>• be a vocationally registered general practitioner.</li></ul> <p>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).</p> <p>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 person being assessed.</p>
<b>Consulting medical practitioner</b>	<p>A registered medical practitioner who accepts a referral to conduct a consulting assessment of the person.</p>



