



Voluntary Assisted
Dying Review Board

Report of operations

July–December 2020

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

It details:

- activity from 1 July to 31 December 2020 as well as since the commencement of the *Voluntary Assisted Dying Act 2017*
- characteristics of applicants who commenced a voluntary assisted dying application from 19 June 2019 to 31 December 2020.

By law, the Board is required to report to Parliament every six months for the first two years.

The next report will be submitted in **August 2021** and will cover the reporting period 1 January to 30 June 2021. This will be the final six-monthly report.

The Board will report each financial year from 2021/22.

More information

bettersafecare.vic.gov.au/vad

Key contacts

Safer Care Victoria secretariat

VADboard@safecare.vic.gov.au

Statewide Voluntary Assisted Dying Care Navigator Service

vadcarenavigator@petermac.org

End of life care policy team, Department of Health

EndofLifecare@dhhs.vic.gov.au

Statewide Pharmacy Service

statewidepharmacy@alfred.org.au



Foreword

It has been more than 18 months since Victoria became the first state in Australia to introduce voluntary assisted dying. As the program continues to mature, information and feedback reiterates how voluntary assisted dying provides Victorians suffering from a terminal illness a genuine and compassionate choice at the end of life.

This report covers the third six-month period of Victoria's *Voluntary Assisted Dying Act 2017* and shows that Victorians continue to seek access to voluntary assisted dying.

The Voluntary Assisted Dying Review Board's previous reports have presented activity and key lessons drawn from case reviews and feedback. In contrast, this report provides mostly activity and data, as the themes identified over the past six months are consistent with those previously reported.

Following interest in providing more information about voluntary assisted dying, the Board is able to share additional data in this report, including more information about the medical practitioners involved in voluntary assisted dying, data from the Statewide Voluntary Assisted Dying Care Navigator Service, feedback provided to the Statewide Pharmacy Service, and further information about withdrawn cases.

In summary, over the past six months:

- **access to voluntary assisted dying has grown** – the number of practitioner administration permits issued increased by 31.6 per cent, and the number of confirmed deaths from practitioner administration increased by 81.8 per cent
- **the number of medical practitioners involved continues to grow** – there was a 25.6 per cent increase in the number of medical practitioners involved in applications, although there is still a gap in some speciality areas and in regional and rural Victoria
- **the Statewide Pharmacy Service experienced greater demand** – the number of applicants receiving medication increased by 30.9 per cent. Despite this, most applicants received their medication on the day they preferred
- **applications were rarely withdrawn due to the applicant deciding not to proceed** – less than two per cent of withdrawn cases were due to the applicant changing their mind
- **compliance with the Act remains high** – 95 per cent of cases retrospectively reviewed by the Board were compliant with the Act. The Board identified six cases to be non-compliant – although the issues were not related to the eligibility of the applicant.

Application timelines

The Board continues to encourage people to initiate conversations about voluntary assisted dying early after being given a terminal diagnosis. Voluntary assisted dying is not an emergency medical procedure and, as previously reported, the application process takes time. Starting early provides greater opportunity to complete the process without additional stress or worry.

Medical practitioner involvement

The number of medical practitioners who have undertaken the training, registered in the portal, and been involved in a voluntary assisted dying case continues to grow. However, there is opportunity for more medical practitioners to become involved in order to allow greater access for applicants across Victoria.

The Board encourages medical practitioners to talk with their colleagues about the experience of being a coordinating or consulting medical practitioner. While it may be time consuming to undertake training and registration, many have reported it can also be extremely rewarding.

Portal upgrade

A project to upgrade the Voluntary Assisted Dying Portal has commenced and will include improved functionality and user experience. These improvements were informed by feedback from portal users in submitting and managing applications.

Additional data fields

The Board has received requests and suggestions for additional data to be made publicly available in these reports. The Board will continue to review these requests and, where possible, will include the capture of these data fields in the portal upgrade. The Board will only report on data that it has the power to collect, that can be captured and analysed electronically, and protects the privacy and identity of individuals.

Commonwealth Criminal Code

The Board continues to acknowledge the impact of the Commonwealth Criminal Code and the inability for medical practitioners to complete assessments via a carriage service such as telehealth. Some medical practitioners have indicated that telehealth is not always adequate for conducting assessments, but there have also been stories about the impact this is having on Victorians who are unable to travel for both health and geographical reasons. This Board continues to urge the Commonwealth to reconsider making an exemption from the Criminal Code for Victorians wishing to access voluntary assisted dying.

The impact of coronavirus (COVID-19)

The coronavirus (COVID-19) pandemic has had an unprecedented impact on the Victorian community. However, there are no reasons or criteria related to coronavirus (COVID-19) that would result in a voluntary assisted dying application. The data shows that people continued to request access to voluntary assisted dying despite the restrictions placed on Victorians.

Thank you

On behalf of the Board, I thank the families, carers and nominated contact people who have supported loved ones through their death. It has been a hard year for many – loved ones who died without being able to say goodbye, people having to isolate for months often without the support of family or friends, employment and security lost, and in some ways worst of all, fear and loneliness. I appreciate the death of a loved one in such uncertain times may have been particularly difficult.

My thanks also to those who kept this important work functioning during such a significant health crisis. This includes the Board members, Safer Care Victoria secretariat, the various Department of Health teams, the Statewide Pharmacy Service, the Statewide Voluntary Assisted Dying Care Navigator Service and the healthcare practitioners that make up a team of people dedicated to ensuring that very ill Victorians have another choice about how their life may end.

The fact that voluntary assisted dying has been able to continue during this time is truly a testament to the work of many people and I wish to acknowledge their dedication.



Betty King

Chairperson
Voluntary Assisted Dying Review Board

Snapshot

Table 1: Requests received

Stage	Status	1 January– 30 June 2020	1 July–31 December 2020	Total to date	
Eligibility	First assessment	Eligible	205	221	562
		Ineligible	6	12	19
	Consulting assessment	Eligible	188	186	483
		Ineligible*	1	4	8
Permit applications	Self-administration permit	Issued	126	149	350
		Not issued	16	12	44
	Practitioner administration permit	Issued	19	25	55
		Not issued	5	7	16
Withdrawn	Case withdrawn from portal by medical practitioner or upon notification of death of applicant**	96	108	239	
Medications dispensed	For self-administration [#]	97	127	281	
Confirmed deaths^{##}	Medication was administered	Medication was self-administered	70	74	184
		Medication was administered by a practitioner	11	20	40

* Ineligible cases may be reassessed and later deemed eligible and so the total number of ineligible cases reported may decrease over time.

** Notification of death was previously received for permit holders only, but now includes all applicants who commence the application process. As a result, there has been an increase in withdrawn cases since the previous report. 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 is removed from the data reported. Any apparent differences between this report and the previous report are due to finalisation and confirmation of duplicate data.

[#] 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 select that the person 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

Medical practitioners are required to successfully complete an online training program prior to participating in voluntary assisted dying. For each voluntary assisted dying case, 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 person being assessed.

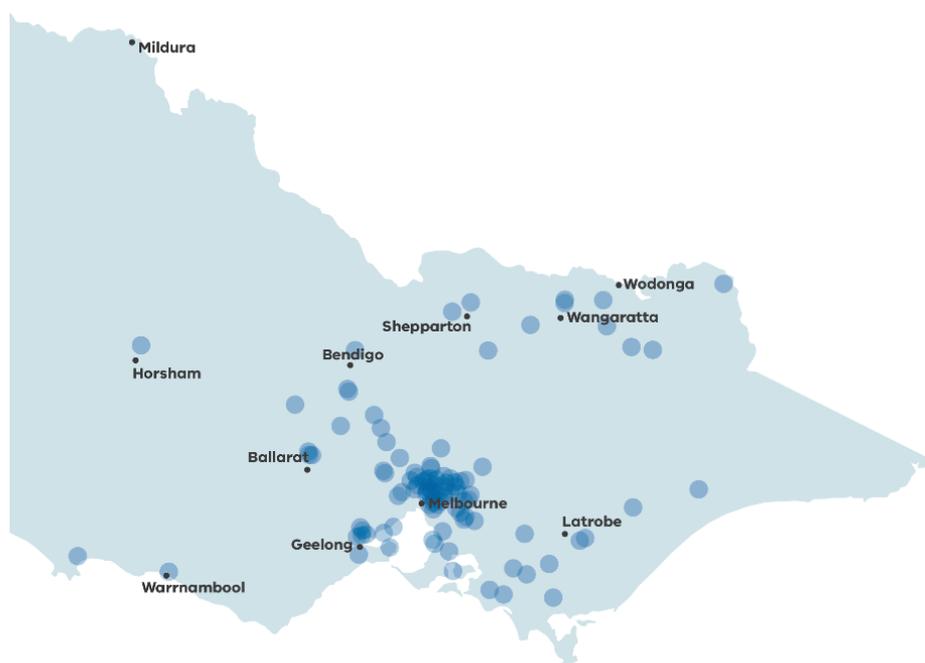
More than 450 medical practitioners have registered for the online training program and just under half of these are registered in the portal to support applications. With all numbers steadily growing in the past six months, the most significant is the 25 per cent increase in the number of medical practitioners supporting at least one active case.

Table 2: Medical practitioner training and involvement

Stage	Description	19 June 2019– 30 June 2020	1 July–31 December 2020	Change (%)
Online training	Medical practitioner registered for the online training program	422	455	7.8%
Portal registration	Medical practitioner registered in the portal	175	210	20.0%
Active in the portal	Medical practitioner involved in one or more case as either coordinating or consulting medical practitioner	125	157	25.6%

More than a third (36 per cent) of registered medical practitioners are located in regional and rural Victoria. This aligns with where voluntary assisted dying applicants live. There remain limited numbers of medical practitioners participating in voluntary assisted dying in eastern and western Victoria.

Figure 1: Location of medical practitioners



While the number of trained medical practitioners has increased, there are still limited numbers of some specialists, such as neurologists, particularly in regional and rural areas.

Table 3: Specialisation of active medical practitioners (1 July–31 December 2020)

Speciality area [^]	Regional and rural	Metropolitan	Total
General practice	53	69	122
Medical oncology	11	25	36
Neurology	0	10	10
General medicine	3	5	8
Respiratory and sleep medicine	0	6	6
Haematology	2	4	6
Palliative medicine	4	1	5
Other [#]	7	29	36

[^] 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 number of medical practitioners included exceeds the number of 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, neurosurgery, pain medicine, psychiatry, radiation oncology, rehabilitation medicine, rheumatology, sexual health medicine and urology, or do not have a specialty area(s) listed on Ahpra.

Peer support among medical practitioners is also growing – there are now 29 trained medical practitioners in a specialist online community of practice who share their experiences and lessons.

- Medical practitioners who have completed the voluntary assisted dying training can join the community of practice by contacting vadcommunity@westvicphn.com.au.
- Other healthcare professionals who support people to access voluntary assisted dying can join a community of practice by contacting vadcarenavigator@petermac.org.

Applicants and assessments

An applicant is a person seeking to access voluntary assisted dying. They must meet all the eligibility criteria, as assessed by their coordinating and consulting medical practitioners.

SEEKING INFORMATION ABOUT VOLUNTARY ASSISTED DYING

The Statewide Voluntary Assisted Dying Care Navigator Service provides information and support to the community, health practitioners and health services across Victoria. Care navigators are based at a metropolitan health service and at a health service in each Victorian region.

In the past six months, the service has provided support to 446 people seeking information about voluntary assisted dying.

Figure 2: Who contacts with the service?

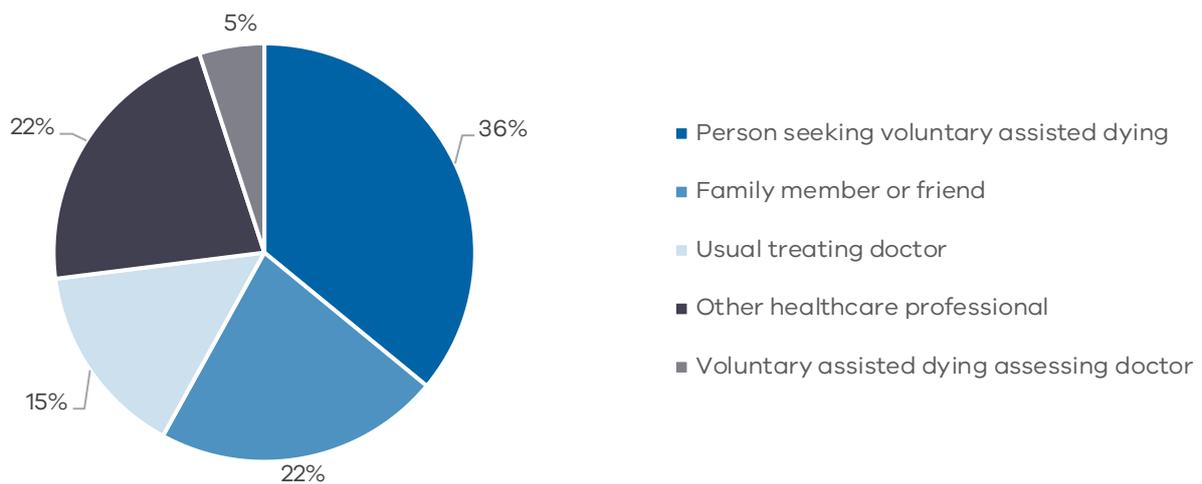
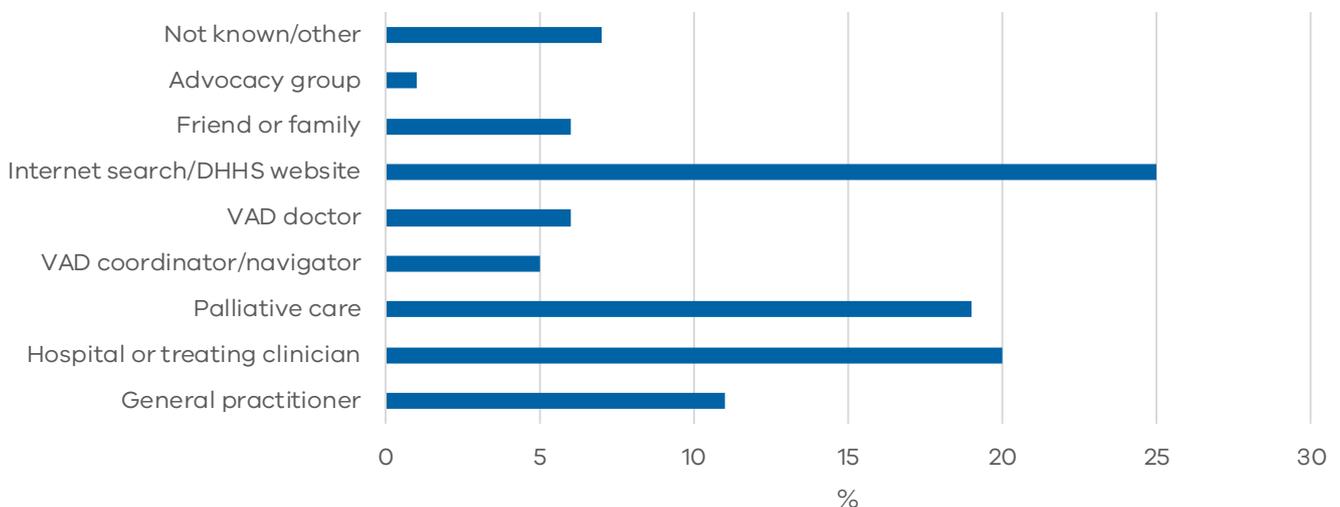


Figure 3: How did they find the service?

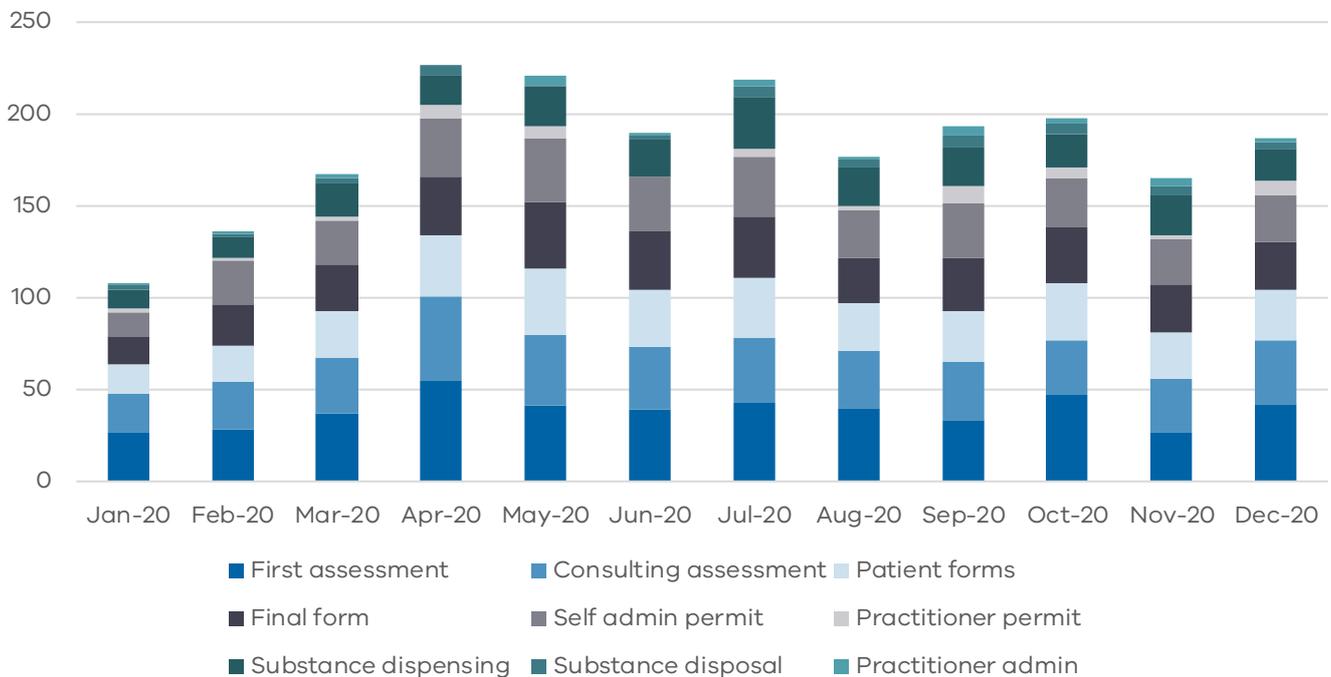


VOLUNTARY ASSISTED DYING APPLICATIONS

The Board continues to see an increase in voluntary assisted dying applications, including those that progress to permit application stage.

Activity and new applications peaked in April 2020, with an average of 182 forms in process each month in 2020.

Figure 4: Forms submitted via the portal (1 January–31 December 2020)



Since the commencement of the Act on 19 June 2019 there have been:

- 17 applicants who were referred for a specialist opinion of their decision-making capacity in relation to voluntary assisted dying
- 41 applicants who were referred to a specialist for a neurodegenerative assessment where their prognosis was likely to be between six to 12 months.

These assessments are required in accordance with the legislation.

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, and 50 per cent within 17 days.

PEOPLE WHO APPLIED FOR VOLUNTARY ASSISTED DYING

From the 581 applications to December 2020, the average age of an applicant was 71 (median 72), although ages have ranged from 20 to 100 years.

Just over half of the applicants were male (52.4 per cent), 47.4 per cent were female and 0.2 per cent self described.

Table 4: Applicant demographics (19 June 2019–31 December 2020)

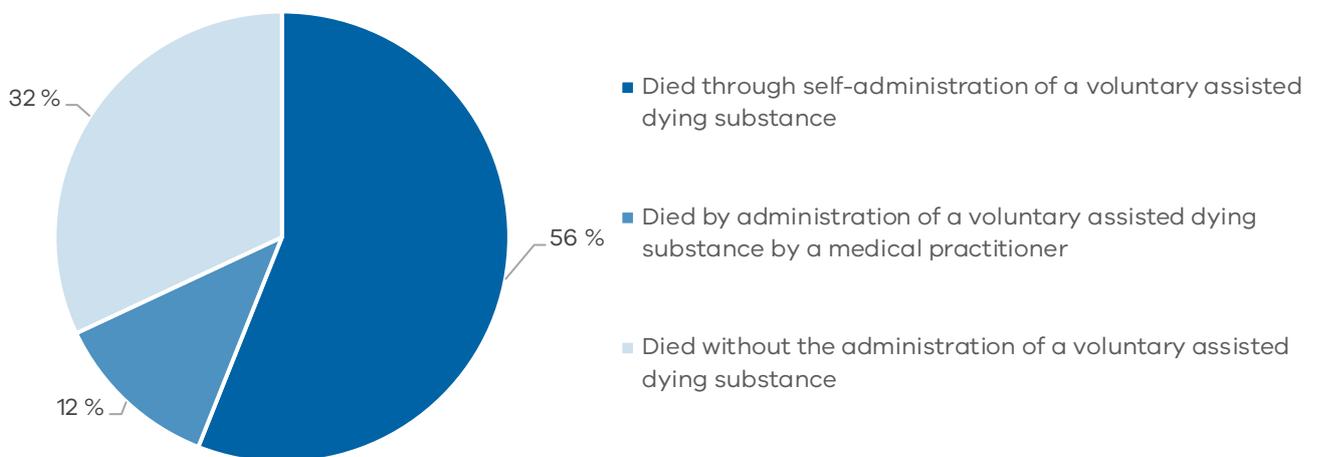
Characteristics [#]	Number	%
Country of birth		
Australia	433	70.3%
Other	166	26.9%
Not provided	17	2.8%
Aboriginal or Torres Strait Islander		
Yes	3	0.5%
No	604	98.0%
Not provided	9	1.5%
Language spoken at home		
English	578	93.8%
Other	25	4.1%
Not provided	13	2.1%
Interpreter required		
Yes	13	2.1%
No	602	97.7%
Unknown	1	0.2%
Residence		
Metropolitan	397	64.4%
Regional/rural	219	35.6%
Living situation		
Private household	537	87.2%
Long-term care or assisted living facility	55	8.9%
Health service	21	3.4%
Not provided	3	0.5%

[#] The demographics of the applicants reflect the information collected and entered in the portal by the medical practitioner who has registered the applicant. Once a medical practitioner has registered an applicant in the portal, a case can be commenced. However, not all applicant registrations will result in cases being commenced and/or the first assessment report being submitted.

VOLUNTARY ASSISTED DYING DEATHS

Of the 328 permit holders who died, 56 per cent administered the medication themselves and 12 per cent had the medication administered by a medical practitioner. The remaining 32 per cent died before the medication was dispensed, or did not take the medication.

Figure 5: Manner of death for all permit holders who died (19 June 2019–31 December 2020)



For all applicants who had a permit issued and have subsequently died, 77 per cent had a malignancy diagnosis and 23 per cent had a non-malignant diagnosis.

Of the malignancy group:

- 21 per cent had a primary lung malignancy
- 11 per cent had a primary breast malignancy
- 11 per cent had a primary pancreatic malignancy
- nine per cent had a primary colorectal malignancy
- nine per cent had other gastrointestinal tract malignancy
- 39 per cent had a range of other malignancies.

Of the non-malignant group:

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

WITHDRAWAL OF CASES

During the six-month reporting period, the Board received access to death notification information for all applicants who commenced the voluntary assisted dying process. This has resulted in cases being withdrawn where death may have occurred prior to July 2020, but are included in the July to December 2020 period. The Board's next report will be more representative of the number of withdrawn cases over this six-month period.

Table 5: Reason for withdrawal (1 July–31 December 2020)

Reason for withdrawal	Number	% *
Coordinating medical practitioner notified of death	48	40.0%
Secretariat notified of death [#]	53	44.2%
Applicant decided not to proceed	2	1.7%
Other ^{**}	17	14.2%

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

[#] 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.

Permit approvals and medication dispensing

The Secretary, Department of Health or their delegate reviews and considers all voluntary assisted dying permit applications. It is the applicant's choice to decide if and when they want to access the voluntary assisted dying medication. The Statewide Pharmacy Service will visit applicants anywhere in Victoria to dispense the medication.

Between 1 July and 31 December 2020, the Secretary, Department of Health issued 174 self-administration or practitioner administration permits. Nineteen permit applications were not issued. Of these:

- 18 were not issued due to administrative errors related to the medications, dosages or formulations. Seventeen of these were corrected, resubmitted and subsequently approved. One application was resubmitted, however the applicant died before the permit was issued
- one was not issued as the applicant was not able to establish eligibility and this case was the subject of an application for review to the Victorian Civil and Administrative Tribunal (VCAT). See page 15 for more information.

TIMELINESS

The Voluntary Assisted Dying Regulations 2018 state that the Secretary, Department of Health has three business days to determine the outcome of a permit application. Once the necessary evidence and forms have been submitted in line with legislative requirements, all permit applications for the reporting period were either issued or not issued within this time period. More than 99 per cent (99.4 per cent) of permit applications' outcomes were determined within two business days.

DISPENSING AND MONITORING MEDICATIONS

Between 1 July and 31 December 2020:

- 87 per cent of applicants had the medication provided on their preferred day of delivery
- 95 per cent of applicants had the medication provided within two business days of their preferred day of delivery
- 65 per cent of medications were dispensed to metropolitan applicants
- 35 per cent of medications were dispensed to regional applicants.

APPLICANT FEEDBACK

Between 19 June 2019 and 31 December 2020, the Statewide Pharmacy Service received feedback from 132 applicants who received the medication:

- 94 per cent of applicants reported that the service was excellent, and the remainder reported the service was good
- 95 per cent of applicants reported that they were visited at a time that suited them.

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 improvement opportunities.

CASE COMPLIANCE

The *Voluntary Assisted Dying Act 2017* was designed to deliver the most conservative and safe legislation in the world, with 68 safeguards and a scrupulous oversight scheme in place. The Act is interpreted in a very strict way, and the Board continues to have a very low threshold for errors or inconsistencies in applications in order to maintain public safety.

Between 1 July and 31 December 2020, the Board found six cases to be non-compliant with the Act.

In two cases, the contact person failed to return unused voluntary assisted dying medication within the legislated 15-day timeframe following the death of the applicant. In both instances, it was returned within a few days of the 15-day period and there was no concern for public safety.

In the remaining four cases, the Board identified an error in the interpretation of the Act by a medical practitioner which resulted in the first request being made to a medical practitioner who did not go on to become the coordinating medical practitioner. This is contrary to the requirements of the Act where the coordinating medical practitioner must be the person who receives and accepts the first request. This error was unintentionally repeated by the medical practitioner on three other occasions.

The Board was satisfied that the cases were clinically appropriate, all eligibility requirements were met and that a misunderstanding had occurred which did not raise concern with the completion of legal requirements. The Board has communicated this to all medical practitioners registered in the portal.

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.

VCAT APPLICATION

The Victorian Civil and Administrative Tribunal (VCAT) can hear applications from eligible parties to review certain decisions through the voluntary assisted dying process. VCAT's jurisdiction is limited to decisions about Victorian residency or a person's decision-making capacity.

During the six-month reporting period, one application for review was brought by a coordinating medical practitioner to VCAT. This was to challenge the Secretary's decision not to issue a self-administration permit due to insufficient evidence of Australian citizenship or permanent residency. Australian citizenship or permanent residency is a mandatory eligibility criterion for accessing voluntary assisted dying.

It was determined at the VCAT directions hearing that VCAT had no jurisdiction to review the Secretary's decision that a person does not satisfy the eligibility criterion of being an Australian citizen or permanent resident. The applicant is actively engaged with the Statewide Voluntary Assisted Dying Care Navigator Service to receive ongoing support.

While people may have lived in Australia and Victoria for many years and consider themselves Australian, the requirements of the Act are clear and require applicants to provide evidence that they are an Australian citizen or permanent resident. The Board is aware that for some people, despite being entitled to live in Australia and Victoria, it can be challenging to establish that they are an Australian citizen or permanent resident. For this reason, the Board encourages applicants to consider the eligibility and documentation requirements as early as possible.

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

