## Voluntary Assisted Dying Board Western Australia

Annual Report **2021–22** 

## Statement of Compliance

The Hon Amber-Jade Sanderson MLA Minister for Health; Mental Health

#### Dear Minister

Pursuant to section 155 of the *Voluntary Assisted Dying Act 2019*, I have pleasure in submitting to you, for presentation to each House of Parliament, the Annual Report of the Voluntary Assisted Dying Board for the year ended 30 June 2022.

**Dr Scott Blackwell** 

Chairperson, Voluntary Assisted Dying Board

16 November 2022

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## Overview

## About this report

This annual report fulfils the requirement of section 155 of the *Voluntary Assisted Dying Act 2019* by reporting on the operations of the *Voluntary Assisted Dying Act 2019* for the 12 months prior to 30 June 2022.

#### Data in this report

The data in this report has been extracted from the Voluntary Assisted Dying Information Management System (VAD-IMS), unless specified otherwise.

VAD-IMS is a bespoke, web-based application developed to manage voluntary assisted dying in Western Australia. Health practitioners upload forms at each stage of the voluntary assisted dying process and can use the platform to register for access to the *Western Australia Voluntary Assisted Dying Approved Training*. VAD-IMS is monitored by the Voluntary Assisted Dying Board Secretariat Unit.

Data was extracted from VAD-IMS on 5 October 2022 to account for activity that occurred prior to 30 June 2022. Footnotes are included throughout the annual report to assist with interpretation of the report. Figures have been rounded to one decimal place, and due to rounding, totals may exceed 100 per cent. Unless specified otherwise, data in the annual report reflects information collected from valid forms only. VAD-IMS also holds data on forms with other status types including void, revoked or invalid. Unless specified, data for region is based on the postcode of the patient's home address, with the Perth metropolitan region including the Peel region.

## **Foreword**

I am pleased to present the first annual report of the Voluntary Assisted Dying Board. The Voluntary Assisted Dying Board was established on 1 July 2021, the day that voluntary assisted dying became an end-of-life choice in Western Australia.

On behalf of the Voluntary Assisted Dying Board, I express condolences to all the family and friends of those who made the choice of voluntary assisted dying and have died in 2021–22. We recognise your loss and wish you well as you grieve. We thank those who have shared their experience of voluntary assisted dying with the Voluntary Assisted Dying Board. You have helped keep our work person-centred.

#### Inaugural annual report

The Voluntary Assisted Dying Board is required to report annually on the operation of the *Voluntary Assisted Dying Act 2019*. The Annual Report 2021–22 provides:

- an overview, including of the events that lead to the implementation, of voluntary assisted dying in Western Australia
- an explanation of the process and those who play an integral part in the process
- data collected during the reporting period
- the themes and challenges that have arisen in the first year of operation of the Voluntary Assisted Dying Act 2019.

Voluntary assisted dying is about a person who knows they will die soon and is suffering in a way that cannot be relieved in a manner that the person considers tolerable. The 'Year in review' describes the people who made the choice to end their lives by voluntary assisted dying, the process of voluntary assisted dying and those who played a role in that process.

Their progress through the necessarily rigorous stages of assessment, final decision and administration is mapped by the data. Though a complex process, the ability of Western Australians to make the lawful choice of voluntary assisted dying, and to traverse the steps required to fulfill that choice, has worked well under the *Voluntary Assisted Dying Act 2019*.

#### Monitoring

Monitoring compliance with the *Voluntary Assisted Dying Act 2019* is the primary responsibility of the Voluntary Assisted Dying Board. The Board has established policies and procedures to maintain the integrity of the process in operation and ensure those who access voluntary assisted dying meet the eligibility criteria.

#### **Recommendations**

During 2021–22, the Voluntary Assisted Dying Board identified key areas for improvement to voluntary assisted dying:

- The need for more practitioners to participate and complete the Western Australian Voluntary Assisted Dying Approved Training.
- Amendments to the Commonwealth Criminal Code Act 1995 relating to the use of a carriage service that has limited the use of Telehealth for voluntary assisted dying in Western Australia.
- Remuneration of participating practitioners who provide voluntary assisted dying services.

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**Implementation** 

- Adequate and ongoing funding to support the operation of the *Voluntary Assisted Dying Act 2019* and access to voluntary assisted dying for eligible Western Australians including regional residents.
- Identification of areas for review of the Voluntary Assisted Dying Act 2019.

These, and further recommendations, are detailed later in the report.

#### Thank you

The Voluntary Assisted Dying Board is mindful that, while the data reveals a clear picture of activity, it is the human element that has made voluntary assisted dying accessible and safe for Western Australians. We, as a community, are deeply indebted to the people who have taken active roles in the operation of voluntary assisted dying across Western Australia. The professional, caring and compassionate qualities that have emerged is a testament to each of them as individuals, and it has been a highlight of the year for the Voluntary Assisted Dying Board as we have been privileged to witness such commitment. The medical practitioners, care navigators and pharmacists have given beyond the normal call of duty to provide comprehensive end of life care to those Western Australians who have made the choice for voluntary assisted dying in 2021–22. These disciplines have invested in high quality teamwork and have formed a Community of Practice through which they share experiences and support each other. The Voluntary Assisted Dying Board expresses its gratitude to this group for the work done in the first year of operation of voluntary assisted dying in Western Australia.

The Voluntary Assisted Dying Board also recognises the important work done by other health practitioners in the Western Australian health system, and private and not-for-profit providers, who have taken a person-centred approach to facilitating the access of those who make a request for voluntary assisted dying. Similarly, we recognise the important work of the palliative care sector to support access to voluntary assisted dying and express our gratitude as we reflect on the data that reveals that most people who request voluntary assisted dying are also in the care of a palliative care team.

The Voluntary Assisted Dying Board recognises the importance of maintaining the integrity of the process as this reflects on the reputation of voluntary assisted dying in the Western Australian community. We thank The Hon Amber-Jade Sanderson, Minister for Health, and The Hon Roger Cook, former Minister for Health, for their enduring commitment and support for voluntary assisted dying in Western Australia. We are also grateful for the support of Dr D J Russell-Weisz, Director General, Department of Health.

The Voluntary Assisted Dying Board recognises the work of the End of Life Care Program Team in the Department of Health who partner with the Board at many levels to maintain the behind the scenes work necessary to keep voluntary assisted dying on course. Their relationship with the Voluntary Assisted Dying Board and the Secretariat Unit is essential to the success of implementation of voluntary assisted dying in in Western Australia. We are grateful to you.

Finally, the Voluntary Assisted Dying Board expresses its gratitude to the very hard-working Secretariat Unit that supports its activity. The work is constant, with little reprieve and, despite some change in personnel, you have carried out your duties to a remarkably high standard and we are grateful to you.

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Dr Scott Blackwell
Chairperson
Voluntary Assisted Dying Board

## Year in review

Voluntary Assisted Dying Act 2019

**Medical practitioners** 

Commenced 1 July 2021

Completed training

50

Participated as a Coordinating, **Consulting or Administering Practitioner** 

People requesting access to voluntary assisted dying

Age

25 - 97

Median age

73

Male

58.1%

**Female** 

41.9%

Resided in metro area

78.8%

Resided in regional area

21.2%

Cancer related diagnosis

68.0%

Receiving palliative care

85.3%

**Process** 

First Request

First Assessment

375

**Consulting Assessment** 

**Final Request** 

Voluntary assisted dying deaths

**Voluntary assisted dying deaths** 

Self-administration

**Practitioner** administration

**43** (22.6%) **147** (77.4%)

**53.7%** of practitioner administration occurred at the patients home

**64.6%** of practitioner administration via intravenous administration

1.1%

of total deaths in Western Australia in 2021–22

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## Personal reflections

The Voluntary Assisted Dying Board receives feedback via personal reflections from those involved in the voluntary assisted dying process, including the patient, their family or practitioners involved in their care.

The Voluntary Assisted Dying Board is thankful for the contributions of those who made personal reflections in 2021–22, which assisted the Board's understanding of voluntary assisted dying in Western Australia. A number of recommendations were shared with statewide services to improve the safety and quality of voluntary assisted dying. Personal reflections have been deidentified to protect the privacy of individuals and may be distressing to some readers.

Themes expressed in personal reflections included:

Appreciation for the care, understanding and respect displayed by Care Navigators and participating practitioners throughout the voluntary assisted dying process

'The respect and caring displayed by... [names removed] ...will be remembered by the family for the rest of our lives. Thank you for making this possible.'

Family member

'The team at the [The Statewide Care Navigator Service] responded fast, with care and understanding. Without them the process would have been too daunting when my husband was under such stress already. When the time came for this last day, he and our family were prepared. With their help we made that last day a warm and loving farewell to look back on with fondness and sorrow.'

Family member

'The empathy shown from the Doctors and the Care Navigators is amazing. It's easy to feel that they do this out of love and respect for people facing death. I have never met such kind and caring people.'

Patient

Gratitude for the implementation of voluntary assisted dying legislation in Western Australia

The personal impact of voluntary assisted dying on practitioners undertaking this important work

'We feel very grateful that voluntary assisted dying was available for my husband when he needed it...Thank you to all who worked to put this legislation in place and a special thank you to the team who helped us with such compassion.'

Family member

'It was hard on me afterwards. My administration went well, he simply went to sleep with no side-effects. But to be at home, simply with family and no other support (because they were a private couple and I respect that) was confronting – hardest thing I have ever done!'

**Coordinating Practitioner** 

'It is such a comfort to know that when pain becomes too much, I have options. I don't want to be in a hospital environment in my last days. This way I can have my death on my terms.'

**Patient** 

'The night before an administration is usually not great, as I flip from side to side sleeplessly rehearsing scenarios for the day ahead (especially if I have to put in an IV cannula) ...

... A friend of mine who is a midwife and has a lot of involvement in stillbirth, came to see me when she knew I was taking on this work. She gave me a box of trinkets and explained her own way of memorialising the little lives that came into and went out of the world so quickly. So I kept her trinkets and added my own, mainly items from the natural world that remind me, in one way or another, of this person and their importance in my life.'

**Coordinating Practitioner** 

## Timeline for the establishment of voluntary assisted dying in Western Australia

On 1 July 2021, voluntary assisted dying became a choice for eligible Western Australians under the *Voluntary Assisted Dying Act 2019*.

Voluntary assisted dying as an end-of-life choice gained support over many decades across the state driven by individuals and civil society organisations. The Parliamentary Joint Select Committee on End-of-Life Choices in its report *My Life, My Choice*, released in August 2018, made recommendations on advance care planning, palliative care and on the implementation of voluntary assisted dying.

A Ministerial Expert Panel was established by the Minister for Health and chaired by Malcom McCusker AC QC. After consulting widely across the state, the *Ministerial Expert Panel on Voluntary Assisted Dying Final Report* was released, which informed the drafting of legislation to introduce voluntary assisted dying in Western Australia.

After lengthy debate in Parliament, the *Voluntary Assisted Dying Bill 2019* passed each House of Parliament at the end of 2019, setting a timeline for implementation by July 2021.

The Voluntary Assisted Dying Implementation Leadership Team was formed in April 2020 and worked in 8 workstreams to prepare for all aspects of implementation.

The Voluntary Assisted Dying Act 2019 commenced on 1 July 2021.

2017-18

#### Aug 2017 - Aug 2018

Joint Select Committee on End-of-Life Choices Report, My Life, My Choice made multiple recommendations, including development of voluntary assisted dying legislation.

2018-19

#### Dec 2018 - Jun 2019

Ministerial Expert Panel on Voluntary Assisted Dying established, consults across Western Australia and prepares the Ministerial Expert Panel on Voluntary Assisted Dying Final Report.

2019

#### Aug 2019

Voluntary Assisted Dying Bill 2019 introduced into Parliament.

#### **Dec 2019**

Voluntary Assisted Dying Bill 2019 passes both houses of Parliament and becomes Voluntary Assisted Dying Act 2019 (with 18-month implementation period).

2020

#### **April 2020**

**Implementation** Leadership Team established by the Department of Health to oversee, coordinate and facilitate implementation. 2021

#### May 2021

**Voluntary Assisted Dying Implementation** Conference held.

#### **June 2021**

Practitioners commenced Western Australian Voluntary Assisted Dying Approved Training.

#### 1 July 2021

Voluntary Assisted Dying Act 2019 commenced in full.

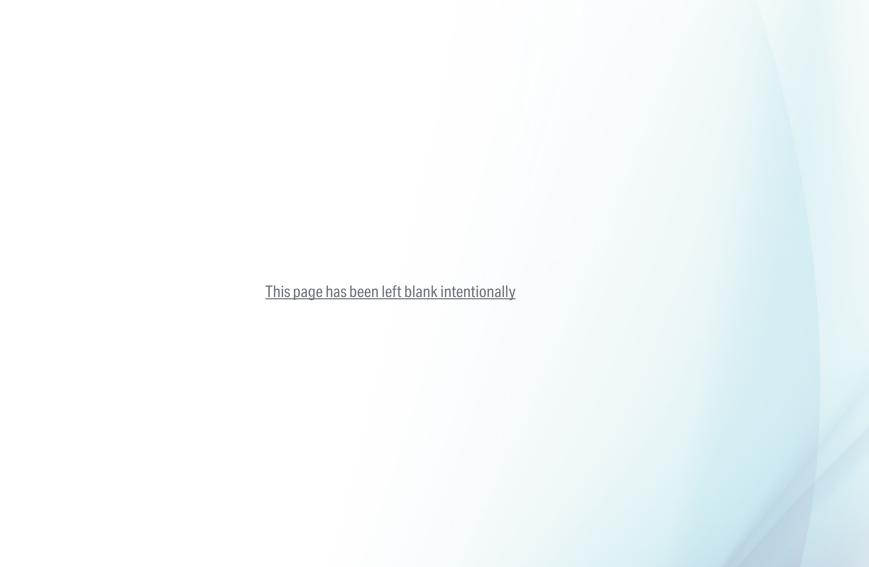
Voluntary Assisted Dying Board officially commenced.

**Voluntary Assisted Dying Information** Management System became operational.

Statewide Care Navigator Service and Statewide Pharmacy Service commenced patient support.

#### 26 July 2021

Voluntary assisted dying accessed in Western Australia for the first time.



# Health practitioners

# Health practitioner participation in voluntary assisted dying

Medical and nurse practitioners participating in the voluntary assisted dying process must meet eligibility criteria as defined in the *Voluntary Assisted Dying Act 2019*, including registration type, practice duration and completion of the *Western Australian Voluntary Assisted Dying Approved Training (WA VAD Approved Training)*. Once training is completed, medical practitioners may complete patient assessments as a Coordinating or Consulting Practitioner. Trained medical and nurse practitioners may administer the voluntary assisted dying substance as an Administering Practitioner.

#### In 2021-22:

- 70 medical practitioners completed the WA VAD Approved Training to enable them to act as a participating practitioner as a Coordinating, Consulting or Administering Practitioner
- 50 medical practitioners (71.4% of participating practitioners¹) acted as a Coordinating, Consulting or Administering Practitioner
- 35 medical practitioners completed First Assessments as a Coordinating Practitioner. Of these:
  - 82.9 per cent of practitioners (n=29) completed more than one First Assessment
  - 40 per cent of practitioners (n=14) completed First Assessments for 11 or more patients
- nearly all patients who underwent a First Assessment did not have a previous relationship with their Coordinating Practitioner (n= 342, 91.2%).

**Implementation** 

<sup>1</sup> Participating Practitioner includes any medical or nurse practitioner who has completed WA VAD Approved Training to enable them to participate in the voluntary assisted dying process as a Coordinating, Consulting or Administering Practitioner.

Table 1: Number of practitioners who completed a First Assessment in 2021–22

Number of patients per practitioner	Number of practitioners	%
1 Patient	6	17.1%
2-10 Patients	15	42.9%
11-20 Patients	7	20.0%
> 20 Patients	7	20.0%
Total	35	100.0%

#### **Location of practice**

In 2021–22, participating medical practitioners had a nominated practice address<sup>2</sup> in all regions except the Wheatbelt. Two thirds of participating practitioners were based in the Perth metropolitan region (n=47, 67.14%).

Table 2: Number of participating practitioners by health region in 2021–22

Region of practice	Number of participating practitioners	%
Perth metropolitan	47	67.1%
Goldfields	1	1.4%
Great Southern	6	8.6%
Kimberley	4	5.7%
Mid West	2	2.9%
Pilbara	2	2.9%
South West	8	11.4%
Wheatbelt	0	0.0%
Total	70	100.0%

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<sup>2</sup> Medical Practitioners nominate their work address when registering to use VAD-IMS.

#### **Practitioner specialty**

Participating practitioners hold registration with a range of specialties<sup>3</sup>. In Western Australia participating medical practitioners are not required to have specialty expertise in the disease, illness or medical condition expected to cause the patient's death. In 2021–22, General Practice was the specialty of 45.9 per cent (n=34) of participating practitioners.

Specialty is sourced from the practitioner's registration with the Australian Health Practitioner Regulation Agency and is recorded in VAD-IMS. The number exceeds the total number of participating practitioners as some practitioners hold more than one registration type.

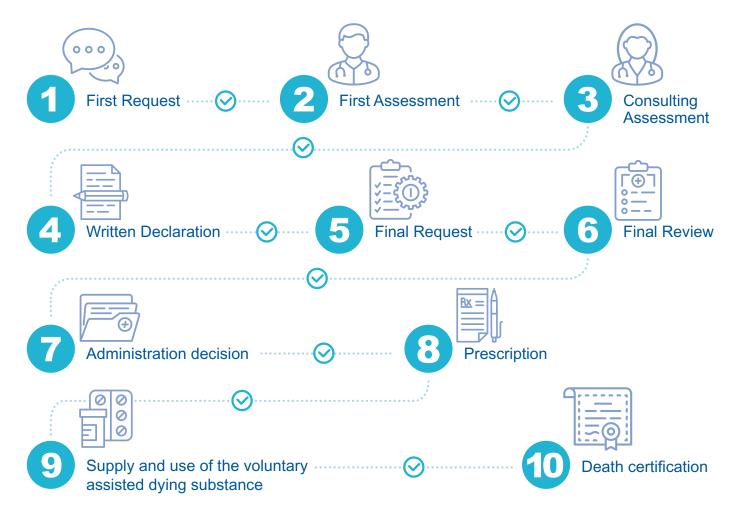
Table 3: Number of participating practitioners by specialty type in 2021–22

Participating practitioner specialty	Number of participating practitioners	%
General practice	34	45.9%
Psychiatry	7	9.5%
Anaesthesia	6	8.1%
Emergency medicine	4	5.4%
Neurology	4	5.4%
Haematology	5	6.8%
Geriatric medicine	3	4.1%
Palliative care	2	2.7%
Clinical pharmacology	1	1.4%
General medicine	1	1.4%
Intensive care medicine	1	1.4%
Medical oncology	1	1.4%
Obstetrics and gynaecology	1	1.4%
Pain medicine	1	1.4%
Paediatrics and child health	1	1.4%
Physician	1	1.4%
Rheumatology	1	1.4%
Total	74	100.0%

# Request and assessment process

## Access to voluntary assisted dying

The voluntary assisted dying process involves several steps from First Request to death certification. Each step is recorded, and a person can choose to stop the process at any point. If a person withdraws, or if they are not considered eligible at First Assessment, they may recommence the request and assessment process by making a new First Request.



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## First Request

A person starts the voluntary assisted dying process by making a First Request to a medical practitioner during a medical consultation. The request must be clear and unambiguous. The medical practitioner must decide whether to accept or refuse the First Request. Once a medical practitioner accepts a First Request, they become the person's Coordinating Practitioner. A First Request may be refused because the medical practitioner is ineligible, unable or unwilling to participate, or because they have conscientious objection to voluntary assisted dying.

Once the First Request has been accepted or refused, the medical practitioner must provide the person making a First Request a copy of the *Approved information for a person making a First Request for voluntary assisted dying booklet* (Approved Information) and notify the Voluntary Assisted Dying Board by submission of the *First Request Form*. The Approved Information contains the contact details of the Statewide Care Navigator Service who can provide information, support and assistance to the person throughout the voluntary assisted dying process. This includes assistance with finding another participating medical practitioner when a First Request has been refused.

#### During 2021-22:

- 533 people made a First Request to access voluntary assisted dying
- 345 people (64.7%) made only one First Request, of which 225 (65.2%) were accepted and 120 (34.8%) were refused
- 188 people (35.3%) made more than one First Request
- 727 First Requests were made as some people made more than one First Request<sup>4</sup>. Of these:
  - 420 (57.8%) requests were accepted
  - 307 (42.2%) requests were refused.

A practitioner being ineligible to participate in the voluntary assisted dying process was the most common reason a First Request was refused (n=105, 34.2%). Conscientious objection to voluntary assisted dying was recorded as the reason in 13 per cent (n=40) of First Requests that were refused.

In 2021–22, First Requests were made by persons residing in each region of Western Australia, with 76.5 per cent (n=556) of First Requests being made in the Perth metropolitan region.

Table 4: Number of First Requests made by health region in 2021–22

Health region of person making a First Request	Number of First Requests	%
Perth metropolitan	556	76.5%
Goldfields	14	1.9%
Great Southern	63	8.7%
Kimberley	7	1.0%
Mid West	16	2.2%
Pilbara	6	0.8%
South West	47	6.5%
Wheatbelt	18	2.5%
Total	727	100%

**Implementation** 

<sup>4</sup> Information is provided based on a First Request being made and a *First Request Form* being submitted to the Voluntary Assisted Dying Board.

## First Assessment

Once a medical practitioner accepts the First Request, they become the Coordinating Practitioner for the patient. The Coordinating Practitioner assesses the patient's eligibility to proceed with voluntary assisted dying through the First Assessment process.

#### In 2021-22:

- 375 patients completed a First Assessment
- 383 First Assessments were completed as some patients had more than one First Assessment<sup>5</sup>, of which:
  - 353 (92.2%) assessments had an eligible outcome
  - 30 (7.8%) assessments had a not eligible outcome.

#### **Eligibility**

At the First Assessment the Coordinating Practitioner determines the patient's eligibility to access voluntary assisted dying. If a patient does not meet the eligibility criteria, they are assessed as ineligible and the voluntary assisted dying process stops.

The *Voluntary Assisted Dying Act 2019* requires that a patient must meet all the following criteria to be eligible for voluntary assisted dying:

- The person has reached 18 years of age.
- The person is an Australian citizen or permanent resident.
- At the time of making a First Request (for voluntary assisted dying), the person has been ordinarily resident in Western Australia for a period of at least 12 months.
- The person is diagnosed with at least one disease, illness or medical condition that:
  - is advanced, progressive and will cause death
  - will, on the balance of probabilities, cause death within a period of 6 months or, in the case of a disease, illness or medical condition that is neurodegenerative, within a period of 12 months
  - is causing suffering to the person that cannot be relieved in a manner the person considers tolerable.
- The person has decision-making capacity in relation to voluntary assisted dying.
- The person is acting voluntarily and without coercion.
- The person's request for access to voluntary assisted dying is enduring.

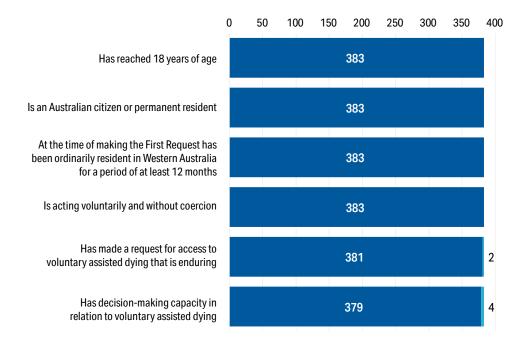
<sup>5</sup> A patient may have completed more than one First Assessment in 2021–22. Scenarios include:

if a patient was assessed as not eligible on an initial assessment and was reassessed and their eligibility changed e.g. their disease progression advanced

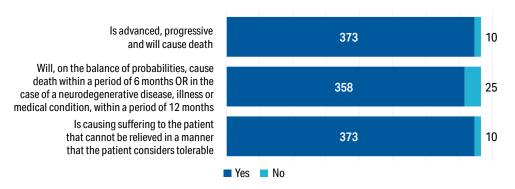
if a patient withdrew from the request and assessment process and then at a subsequent date made a new First Request.

In 2021–22, the most common reason patients were found to be ineligible was because they had not been diagnosed with at least one disease, illness or medical condition that would, on the balance of probabilities, cause death within a period of 6 months or in the case of a neurodegenerative disease, illness or medical condition, within a period of 12 months.

Figure 1: Eligibility of patients undertaking First Assessment in 2021–22



Has been diagnosed with at least one disease, illness or medical condition that:



During the First Assessment, a Coordinating Practitioner may make a referral to another medical practitioner for determination that the patient:

- meets eligibility criteria related to disease, illness or medical condition
- has decision-making capacity in relation to voluntary assisted dying
- is acting voluntarily and without coercion.

In 2021–22, 8 referrals for determination were made. All referrals were made for a determination on the patient's disease, illness or medical condition.

## Profile of eligible patients requesting access to voluntary assisted dying

In 2021–22, 353 patients were assessed as eligible to access voluntary assisted dying after the completion of a First Assessment.

#### For 2021-22:

- eligible patients were aged 25 to 97 years old, with a median age of 73
- more than half of eligible patients were male (male n=205, 58.1%; female n=148, 41.9%)
- more than three quarters of eligible patients (n=278, 78.8%) resided in the Perth metropolitan region
- 1.7 per cent of patients (n=6) were of Aboriginal origin
- approximately 1 in 10 patients (n=35, 9.9%) did not consider English to be their first language.

Table 5: Demographic characteristics of patients assessed as eligible for voluntary assisted dying in 2021–22

Characteristic	Number of patients	%
Patient age		
18–29	2	0.6%
30–39	3	0.8%
40–49	9	2.5%
50–59	29	8.2%
60–69	83	23.5%
70–79	119	33.7%
80–89	81	22.9%
90+	27	7.6%
Patient region		
Perth metropolitan	278	78.8%
Goldfields	8	2.3%
Great Southern	21	5.9%
Kimberley	4	1.1%
Mid West	8	2.3%
Pilbara	3	0.8%
South West	19	5.4%
Wheatbelt	12	3.4%

Characteristic	Number of patients	%
Gender		
Male	205	58.1%
Female	148	41.9%
Other	0	0.0%
Aboriginal or Torres Strait Islander origin		
No	347	98.3%
Aboriginal	6	1.7%
Torres Strait Islander	0	0.0%
Aboriginal and Torres Strait Islander	0	0.0%
Born overseas		
No	206	58.4%
Yes	147	41.6%
English first language		
No	35	9.9%
Yes	318	90.1%
How well does the patient speak English		
Not at all	2	0.6%
Not well	1	0.3%
Well	16	4.5%
Very well	334	94.6%

Characteristic	Number of patients	%
Patient ancestry		
Australian	150	42.5%
Dutch	13	3.7%
English	107	30.3%
Indian	7	2.0%
Irish	11	3.1%
Italian	11	3.1%
Other	43	12.2%
Scottish	11	3.1%
Assisted by interpreter during First Assess	ment	
No	351	99.4%
Yes	2	0.6%
Relationship status		
Divorced	60	17.0%
Married/De facto	175	49.6%
Never married	29	8.2%
Separated	17	4.8%
Widowed	71	20.1%
Not reported	1	0.3%

Characteristic	Number of patients	%
Usual living circumstances		
Lives with family	214	60.6%
Lives alone	115	32.6%
Lives with others	24	6.8%
Highest level of education		
Primary school	10	2.8%
High school	137	38.8%
Year 12 graduation	51	14.4%
Trade certificate	42	11.9%
Advanced Diploma and Diploma	38	10.8%
Bachelor degree	49	13.9%
Postgraduate degree	26	7.4%

#### **Primary diagnosis**

Patients found eligible to access voluntary assisted dying had a range of primary diagnoses. More than two thirds of eligible patients (n=240, 68.0%) were reported as having a cancer related diagnosis. 'Other' diagnoses included congestive heart failure, end stage renal failure and peripheral vascular disease.

Table 6: Number of patients by primary diagnosis group in 2021–22

Diagnostic group	Number of patients	%
Cancer-related	240	68.0%
Neurological	51	14.4%
Other	32	9.1%
Respiratory-related	30	8.5%
Total	353	100%

#### Reason for accessing voluntary assisted dying

Patients are eligible to access voluntary assisted dying if they meet all eligibility criteria including having at least one disease, illness or medical condition that will on the balance of probabilities cause death within a period of 6 months, or 12 months for neurodegenerative conditions, and is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable. During the First Assessment, while not part of the assessment of eligibility, patients are asked to nominate their reasons for requesting voluntary assisted dying from a list of options given.

In 2021–22, the most common reasons given by patients assessed as eligible during the First Assessment were being less able to engage in activities making life enjoyable, or concern about it (71.1%); losing autonomy, or concern about it (66.3%) and loss of dignity, or concern about it (57.2%).

#### **Palliative care**

Patients in Western Australia have several end of life care choices including advance care planning, palliative care services and voluntary assisted dying. Palliative care aims to improve the quality of life of anyone with a life-limiting condition, their family and carers and plays an important role in how a person approaches the end of their life. During the First Assessment process, patients are asked if they are currently receiving, or have previously received, palliative care.

In 2021–22, for patients assessed as eligible during the First Assessment, most were receiving palliative care at the time of the First Assessment (n=301, 85.3%). Patients were most commonly receiving community or home-based palliative care at the time of the First Assessment (56.5%).

Table 7: Palliative care information collected during First Assessment in 2021–226

Patients receiving palliative care at time of First Assessment		Number of patients	%
No		52	14.7%
If no, have they	No	43	82.7%
received within last 12 months?	Yes	9	17.3%
Yes		301	85.3%
If yes, from where?	Community or home-based palliative care	170	56.5%
	Specialist palliative care unit	63	20.9%
	General practitioner	57	18.9%
	Consultation in a hospital	55	18.3%
	Outpatient clinic	23	7.6%
	Consultation in a facility	12	4.0%
Total		353	100%

## **Consultation Assessment**

Once a patient has been assessed as eligible for voluntary assisted dying during the First Assessment, the Coordinating Practitioner must refer the patient to another medical practitioner for a Consulting Assessment. The Consulting Practitioner conducts an independent assessment of the patient's eligibility for voluntary assisted dying.

- 321 patients completed a Consulting Assessment. Of these:
  - 317 patients were found eligible
  - 4 patients found eligible during the First Assessment were then found not eligible during the Consulting Assessment
- 324 Consulting Assessments were completed as some patients had more than one Consulting Assessment.

<sup>6</sup> For patients currently receiving palliative care, more than one care type can be recorded.

## Final Requests

Patients found eligible after a Consulting Assessment then complete a Written Declaration, before making a Final Request to the Coordinating Practitioner for access to voluntary assisted dying. The *Voluntary Assisted Dying Act 2019* specifies a designated period of 9 days between the First Request and Final Request. An exception to the 9-day designated period can be made if both the Coordinating Practitioner and Consulting Practitioner believe the patient is likely to die or to lose decision-making capacity in relation to voluntary assisted dying before the end of the 9-day designated period.

#### For 2021-22:

- 284 patients submitted a Final Request
- 49 patients made the Final Request within the 9-day designated period.
- Of these:
  - 20 Final Requests were made because it was the opinion of the Coordinating Practitioner that the patient was likely to die before the end of the 9-day designated period
  - 29 Final Requests were made because it was the opinion of the Coordinating Practitioner that the patient would lose decision making capacity in relation to voluntary assisted dying before the end of the 9-day designated period.

Whilst a patient can make the Final Request in the designated period this data does not represent patients who went onto administer the voluntary assisted dying substance within the designated period.

## **Administration Decision**

The request and assessment process concludes with the Final Review. If the patient has been confirmed as eligible at the Final Review, they may make an Administration Decision. This decision is made in consultation with, and on the advice of, the Coordinating Practitioner. Administration of the voluntary assisted dying substance may be through one of two options:

- 1. self-administration
- 2. practitioner administration.

Self-administration of a voluntary assisted dying substance requires the patient to prepare and ingest the substance by swallowing or via a percutaneous endoscopic gastrostomy (PEG) or nasogastric (NG) tube. The patient must be able to complete these actions entirely by themselves. If a patient is unable to independently undertake these actions or is concerned about their ability to undertake these actions, self-administration is not a suitable option and a practitioner administration decision is made. Practitioner administration of a voluntary assisted dying substance may be assisted oral ingestion, assisted ingestion via PEG or NG tube, or intravenous administration.

The data shows that there has been a preference amongst patients for the voluntary assisted dying substance to be administered by an Administering Practitioner due to concerns about the patient's ability to administer the substance.

#### In 2021-22:

- 275 patients made an Administration Decision. Of these:
  - 189 patients (68.7%) made a practitioner administration decision
  - 86 patients (31.3%) made a self-administration decision
- 10 patients made more than one Administration Decision.

More than one Administration Decision may be made if a patient changes their administration option (from self-administration to practitioner administration or vice versa).

The prescription process can commence after an Administration Decision has been made and, in the case of self-administration, after the appointment of a Contact Person who will have obligations under the Voluntary Assisted Dying Act 2019, including notifying the Coordinating Practitioner if the patient dies and giving any unused voluntary assisted dying substance to an Authorised Disposer.

## Supply of the voluntary assisted dying substance

Supply of the voluntary assisted dying substance is a tightly controlled process initiated at the request of the patient. An Authorised Supplier at the Statewide Pharmacy Service may supply the voluntary assisted dying substance on receipt and authentication of a prescription from the Coordinating Practitioner. If the patient has decided to self-administer, the Authorised Supplier can supply the voluntary assisted dying substance directly to the patient, their Contact Person or to someone else collecting the substance on the patient's behalf.

The Statewide Pharmacy Service travel to regional locations to ensure access to the voluntary assisted dying substance and to provide supporting information for patients across Western Australia. If the patient has decided to have the voluntary assisted dying substance administered by a medical practitioner or nurse practitioner (known as the Administering Practitioner), the Authorised Supplier will supply the substance directly to the Administering Practitioner (who will take responsibility for the substance until it is used).

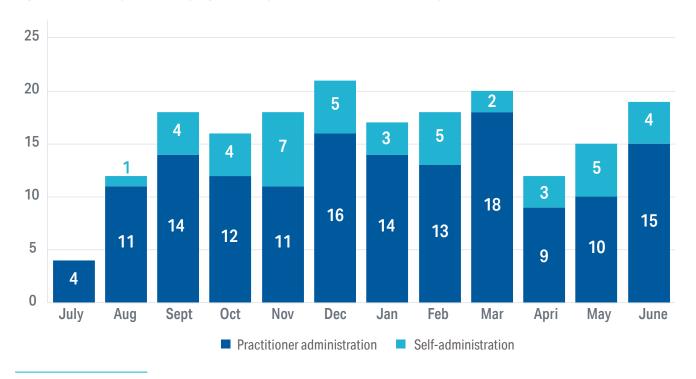
- 231 patients, Contact Persons or Administering Practitioners were supplied a voluntary assisted dying substance
- 6 patients had more than one supply, due to changing from a self-administration to a practitioner administration or substance expiry
- 237 supplies occurred. This included:
  - 161 (67.9%) supplies of the substance for practitioner administration
  - 76 (32.1%) supplies of the substance for self-administration.

## Deaths

## Voluntary assisted dying deaths

- there were 190 deaths recorded following administration of a voluntary assisted dying substance
- voluntary assisted dying deaths represented 1.1 per cent of the 16,702 total deaths in Western Australia<sup>7</sup>
- 147 (77.4 %) patients died via practitioner administration of a voluntary assisted dying substance
- 43 (22.6 %) patients died via self-administration of a voluntary assisted dying substance
- 80 patients who had commenced the request and assessment process died prior to administration of a voluntary assisted dying substance.

Figure 2: Voluntary assisted dying deaths by month and administration type in 2021–22



<sup>7</sup> Total deaths sourced from The Registry of Births, Deaths and Marriages, Department of Justice (2022).

Approximately three quarters of deaths (n=139, 73.2%) following administration of a voluntary assisted dying substance in 2021–22 occurred in patients who resided in the Perth metropolitan region.

Table 8: Number of patient deaths by administration type and health region in 2021–228

	Perth metropolitan		Regional		
Administration type	Number of deaths	%	Number of deaths	%	Total
Practitioner administration	102	53.7%	45	23.7%	147
Self-administration	37	19.5%	6	3.2%	43
Total	139	73.2%	51	26.8%	190

#### In 2021-22:

- the age range of patients when they died was between 25 and 97 years
- the median age of patients when they died was 74 years.

#### 8 Data is based on the patient's home address.

#### **Practitioner administration**

Practitioner administration of the voluntary assisted dying substance was most likely to occur in the patient's home (n=79, 53.7% of deaths), followed by public hospital (ward other than palliative care unit) (n=29, 19.7% of deaths)<sup>9</sup>.

Table 9: Number of patient deaths by practitioner administration location in 2021–22

Practitioner administration location	Number of deaths	%
Patient's home	79	53.7%
Public hospital (ward other than palliative care unit)	29	19.7%
Residential aged care	19	12.9%
Hospice or palliative care unit	14	9.5%
Private residence (other than patient's home)	5	3.4%
Private hospital (ward other than palliative care unit)	1	0.7%
Total	147	100%

- practitioner administration of the voluntary assisted dying substance occurred via intravenous administration in approximately two thirds of cases (n=95, 64.6%)
- the median time to death for practitioner intravenous administration was 8 minutes
- the median time to death for practitioner assisted oral ingestion or assisted ingestion via PEG or NG tube was 15 minutes.

<sup>9</sup> No data on administration location, length of time to death or complications is collected by the Voluntary Assisted Dying Board regarding deaths occurring via self-administration of the voluntary assisted dying substance.

Table 10: Length of time to death of patient by practitioner administration protocol in 2021–22

Length of time to death	Number of administrations via assisted oral ingestion, assisted ingestion via PEG or NG tube	Number of administrations via intravenous administration	Total
< 10 minutes	4	66	70
10 to 30 minutes	38	28	66
31 to 60 minutes	5	1	6
> 60 minutes	5	0	5
Total	52	95	147

#### In 2021-22:

- 97.3 per cent of deaths (n=143) following practitioner administration were reported without complication
- 2.7 per cent of deaths (n=4) following practitioner administration were reported with a complication.

All complications were reported following practitioner assisted oral ingestion and related to regurgitation/vomiting, coughing and the length of time for the substance to take effect. All patients with reported complications died after administration of the voluntary assisted dying substance. The Voluntary Assisted Board completed case reviews of all reported complications.

## Implementation

## Notifications to the Voluntary Assisted Dying Board

The Voluntary Assisted Dying Board receives notifications, via submission of approved forms, at each stage of the voluntary assisted dying process as required by the *Voluntary Assisted Dying Act 2019*.

#### In 2021–22:

- 3,710 forms<sup>10, 11</sup> were received, with 77 per cent of activity from Perth metropolitan and 23 per cent from regional areas
- form submission activity peaked in November and December, with activity stabilising during the second 6 months of implementation
- an average of 309 forms were received each month.

Submission of forms ensure that the Board is notified progressively of the patient's participation in the voluntary assisted dying process, including the outcome of each assessment and to confirm compliance with the *Voluntary Assisted Dying Act 2019*. Voluntary Assisted Dying – Information Management System (VAD-IMS) is the online platform by which practitioners can submit forms to the Voluntary Assisted Dying Board.

**Implementation** 

<sup>10</sup> The number of forms submitted does not constitute the number of individual persons requesting access to voluntary assisted dying, nor the activity at each stage of the process.

<sup>11</sup> The data includes forms with a status of valid, void and revoked. A valid form is considered complete and correct at the time of submission to the Voluntary Assisted Dying Board. Forms that are assigned a status of void or revoked were previously valid forms:

A form is assigned a status of 'void' when a subsequent Consulting Assessment Form is submitted, or a form has been superseded by another valid submission.

An Administration Decision and Prescription Form or Contact Person Appointment Form is assigned a status of 'revoked' when a patient has revoked their administration decision or appointment of a Contact Person.

Table 11: Number of forms with a status of valid, void and revoked by health region submitted in 2021–22

	Total	Perth me	etropolitan	Reç	jional
Form title	Count	Count	%	%	Total
First Request	738	562	76.2%	176	23.8%
First Assessment	384	301	78.4%	83	21.6%
Consultation Referral	337	262	77.7%	75	22.3%
Consulting Assessment	325	254	78.2%	71	21.8%
Written Declaration	294	230	78.2%	64	21.8%
Final Request	284	222	78.2%	62	21.8%
Final Review	285	223	78.2%	62	21.8%
Administration Decision and Prescription	286	222	77.6%	64	22.4%
Contact Person Appointment	93	82	88.2%	11	11.8%
Authorised Supply	237	176	74.3%	61	25.7%
Practitioner Administration	147	103	70.1%	44	29.9%
Authorised Disposal	13	9	69.2%	4	30.8%
Administering Practitioner Disposal	90	63	70.0%	27	30.0%
Notification of Death – Coordinating/Administering Practitioner	149	115	77.2%	34	22.8%
Notification of Death – Other Medical Practitioner	4	4	100.0%	0	0.0%
Revocation	11	6	54.5%	5	45.5%
Coordinating Practitioner Transfer	17	11	64.7%	6	35.3%
Administering Practitioner Transfer	16	12	75.0%	4	25.0%
Total	3,710	2,857	77.0%	853	23.0%

## Statewide services to support voluntary assisted dying

The Department of Heath facilitates access to voluntary assisted dying for eligible Western Australians by providing:

- information, training and support through the End of Life Care Program
- information, coordination and support through the Statewide Care **Navigator Service**
- services for the supply of the voluntary assisted dying substance through the Statewide Pharmacy Service.

#### **End of Life Care Program**

The End of Life Care Program team provide a suite of information and educational resources to support provision of voluntary assisted dying in Western Australia. These include information sheets for patients, patient families and carers, and practitioners; the Western Australian Voluntary Assisted Dying Guidelines; WA VAD Approved Training; online learning; and videos of webinar presentations, all of which are available through the Department of Health website.

The End of Life Care Program manages the promotion and provision of access to the WA VAD Approved Training and verifies components of practitioner eligibility prior to the practitioner being granted access to the online training.

#### **Statewide Care Navigator Service**

The Statewide Care Navigator Service was established by the Department of Health to provide information, support and assistance to anyone involved with voluntary assisted dying, including patients, patient families and carers, practitioners and other service providers.

The legislative requirements of the First Request include the mandatory provision of Approved Information to the person making the request, which contains the Statewide Care Navigator Service contact details. The Statewide Care Navigator Service is pivotal to the success of voluntary assisted dying in Western Australia.

The Care Navigators provide information about voluntary assisted dying in Western Australia, help make the connection with a practitioner who is willing and eligible to participate in voluntary assisted dying, assist people to access available support services and coordinate care for patients throughout the voluntary assisted dying process.

During 2021–22, the Statewide Care Navigator Service<sup>12</sup>:

- recorded more than 10,000 interactions with patients, families and carers, practitioners or service providers
- had an average of 45 new patients each month
- carried an average caseload of 120 patients (combined new referrals and ongoing follow ups).

The Statewide Care Navigator Service provided a range of support services during 2021–22 with ongoing care being the most common type of interaction (n=2030, 36.3%). More than 10 per cent of interactions (n=629) related to assistance in finding a participating practitioner.

<sup>12</sup> Data supplied by the Statewide Care Navigator Service.

**Table 12: Statewide Care Navigator Service interactions in 2021–22<sup>13</sup>** 

Primary interaction type	Number of interactions	%
Ongoing care	2,030	36.3%
Care coordination	1,780	31.9%
Enquiry/information request	901	16.1%
Seeking practitioner	629	11.3%
Other	212	3.8%
RASS and support request	17	0.3%
Not specified	18	0.3%
Total	5,587	100.0%

The Regional Access Support Scheme (RASS) was established to provide financial support for travel for practitioners, patients, support persons and interpreters involved in the voluntary assisted dying process. In 2021–22, there were a total of 108 requests that met the defined Regional Access Support Scheme criteria in support of 50 patients<sup>12</sup>. Almost all requests (n=104, 96%) were made for travel of a practitioner to a patient for face-to-face care. Regional Access Support Scheme requests were received from all but one region.

Table 13: Regional Access Support Scheme Requests by health region in 2021–22

Region	Number of approved Regional Access Support Scheme requests	%
Goldfields	13	12.0%
Kimberley	2	1.9%
Mid West	0	0.0%
Great Southern	22	20.4%
Peel	29	26.9%
Pilbara	2	1.9%
South West	22	20.4%
Wheatbelt	18	16.7%
Total	108	100.0%

<sup>12</sup> Data supplied by the Statewide Care Navigator Service.

<sup>13</sup> Bereavement support was initially captured in 'Other' and will be reported separately in 2022–23.

#### **Statewide Pharmacy Service**

The <u>Statewide Pharmacy Service</u> was established to ensure that the voluntary assisted dying substance is provided in a manner that is safe, equitable, patient-centred and meets regulatory requirements for the handling of such medicines. The Statewide Pharmacy Service has ensured access to substances approved by the Chief Executive Officer of the Department of Health that are required for self-administration and practitioner administration, including oral and intravenous protocols. The role of Statewide Pharmacy Service pharmacists as Authorised Suppliers ensures the substances are provided directly to the patient or their representative, or to the Administering Practitioner.

During 2021–22, the Statewide Pharmacy Service<sup>14</sup>:

- supplied the prescribed voluntary assisted dying substance on 237 occasions
- number of visits per month for supply ranged from 5 to 31
- travelled to every region to supply the voluntary assisted dying substance to patients, Contact Persons or Administering Practitioners (Perth metropolitan n=203, 85.7%; regional n=34, 14.3%)<sup>15</sup>.

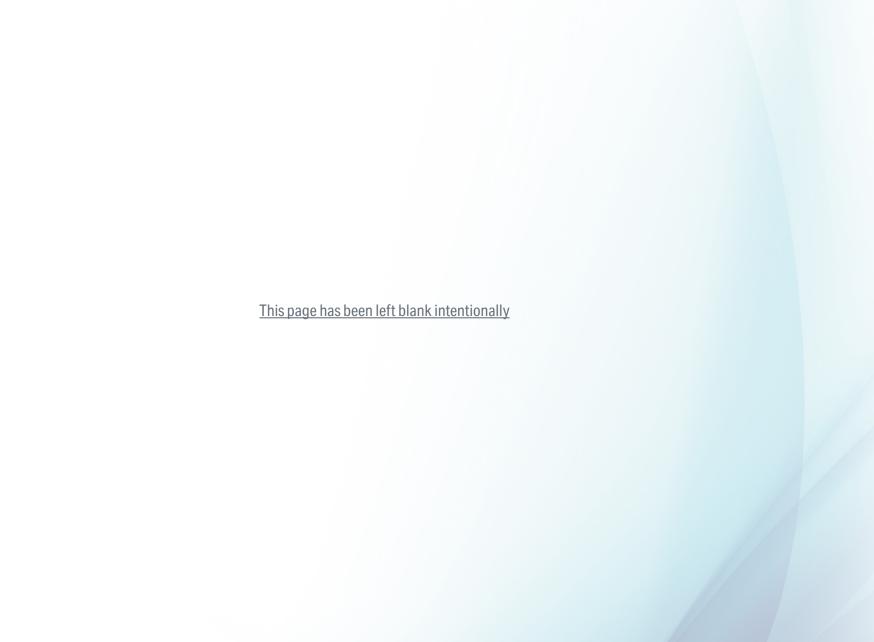
Over 99 per cent (n=236) of supplies occurred within 2 business days (Perth metropolitan) and 5 business days (regional) of the patient or Administering Practitioner's requested timeframe. One supply event occurred outside of the requested timeframe due to a flight cancellation.

#### **Community of Practice**

The Community of Practice is an informal collegial group. It is composed of health practitioners who have completed the WA VAD Approved Training and staff from the Statewide Care Navigator Service and Statewide Pharmacy Service. The Community of Practice meets monthly to support and learn from each other's experiences. There are also opportunities to engage with practitioners across Australia and internationally. The Community of Practice is primarily online with regular opportunities to meet in person. Support for the Community of Practice is provided by the Statewide Care Navigator Service. Participating practitioners wishing to join the Community of Practice can contact VADcarenavigator@health.wa.gov.au

<sup>14</sup> Data supplied by the Statewide Pharmacy Service.

<sup>15</sup> Region where supply of the voluntary assisted dying substance occurs may not align with the patients home address. e.g. Supply of a voluntary assisted dying substance for regional residents may occur in the Perth metropolitan region.



## Voluntary Assisted **Dying Board**

## Voluntary Assisted Dying Board

The Voluntary Assisted Dying Act 2019 provides for the establishment of the Voluntary Assisted Dying Board. The Board was established to ensure proper adherence to the Voluntary Assisted Dying Act 2019 and to recommend safety and quality improvements.

#### **Functions**

The Voluntary Assisted Dying Act 2019 sets out the following functions for the Voluntary Assisted Dying Board:

- to monitor the operation of the Act
- to provide to the Minister for Health or the Chief Executive Officer of the Department of Health, on its own initiative or on request, advice, information and reports on matters relating to the operation of the Act, including any recommendations for the improvements of voluntary assisted dying
- to refer to any of the following persons or bodies any matter identified by the Board in relation to voluntary assisted dying that is relevant to the functions of the Commissioner of Police, the Registrar of Births, Deaths and Marriages, the State Coroner, the Chief Executive Officer of the Department of Health, Chief Executive Officer of the department of the Public Service principally assisting in the administration of the *Prisons* Act 1981, the Australian Health Practitioner Regulation Agency and the Director of the Health and **Disability Services Complaints Office**
- to conduct analysis of, and research in relation to, information given to the Board under the Act
- to collect, use and disclose information given to the Board under the Act for the purposes of performing its functions
- any other function given to the Board under the Act.

## Membership

The Voluntary Assisted Dying Board consists of 5 members appointed by the Minister for Health for a period of up to 3 years with possible reappointment for subsequent terms.

Dr Scott Blackwell: The Board is chaired by General Practitioner and former Australian Medical Association WA Branch President, Dr Scott Blackwell. Dr Blackwell has expertise in palliative and aged care and has chaired the Implementation Leadership Team on voluntary assisted dying.

Hon Colin Holt (Deputy chairperson): Mr Holt recently retired as Member of the Legislative Council for the Southwest Region of Western Australia. He was also Deputy Chairperson of the Joint Select Committee on End-of-Life Choices.

Dr Robert Edis: Dr Edis is a Consultant Neurologist with a particular interest in motor neurone disease and is the Vice President of the Motor Neurone Disease Association of WA.

Ms Maria Osman: Ms Osman is a senior consultant and advisor specialising in human rights, diversity and gender matters and is a former executive director of the WA Offices of Multicultural Interests and Women's Policy. She was on the Ministerial Expert Panel on voluntary assisted dying.

Ms Linda Savage: Ms Savage is a former Director of the Social Security Appeals Tribunal and a legal member of the Administrative Appeals Tribunal. She has also been a Member of the Legislative Council of Western Australia.

#### Meetings

The Voluntary Assisted Dying Board met for the first time on 2 July 2021 and met monthly throughout 2021–22, with all members in attendance for each meeting. Additional workshops were held for risk and audit and planning for the annual report. All meetings were held in accordance with the requirements of the *Voluntary Assisted Dying Act 2019*.

#### **Voluntary Assisted Dying Board Secretariat Unit**

The Voluntary Assisted Dying Board Secretariat Unit supports the day-to-day operations of the Board, including the management of VAD-IMS, facilitating Board meetings and implementing Board decisions. Through the Secretariat Unit, the Department of Health provides corporate services, human resource support, records management, information and communications technology and other services to support the Voluntary Assisted Dying Board to deliver its functions and legislated obligations.

#### **Directions and disclosures**

In 2021–22, no directions were given by the Minister pursuant to section 123(1) or 152(2) of the *Voluntary Assisted Dying Act 2019*.

No disclosures of material or personal interest made by Voluntary Assisted Dying Board Members under section 140(1) relate to matters dealt with in this annual report.

#### Compliance with public sector standards and ethical codes

The *Voluntary Assisted Dying Board Code of Conduct* sets out the responsibilities and obligations of members of the Board and is the foundation on which the Board can provide good governance in its role. It was developed in line with the Public Sector Commission's *Conduct Guide for Public Sector Boards and Committees*. The Code of Conduct was endorsed at the inaugural Voluntary Assisted Dying Board meeting. For 2021–22, there were no issues in relation to the *Voluntary Assisted Dying Board Code of Conduct*.

## Monitoring

The Voluntary Assisted Dying Board is responsible for monitoring the operation of the *Voluntary Assisted Dying Act 2019*. In 2021–22, the Voluntary Assisted Dying Board developed policies and procedures to ensure real time and routine monitoring of compliance with the *Voluntary Assisted Dying Act 2019*. The *Voluntary Assisted Dying Board Monitoring Function Policy* details the principles and processes that guide Board's monitoring functions.

### **Voluntary Assisted Dying Board Secretariat Unit**

The Voluntary Assisted Dying Board Secretariat Unit supports the Board by monitoring VAD-IMS and engaging with participating practitioners to ensure the accurate completion of forms throughout the voluntary assisted dying process through daily monitoring and weekly compliance reviews.

### **Case reviews**

The Voluntary Assisted Dying Board undertakes retrospective monitoring by case reviews of closed individual patient episodes to ensure compliance with the *Voluntary Assisted Dying Act 2019*. On a monthly basis the Voluntary Assisted Dying Board reviews 20 per cent of closed episodes. A patient episode may be closed at various points during the voluntary assisted dying process, including if the patient has died from taking or being administered a voluntary assisted dying substance; died not by voluntary assisted dying or has withdrawn from the process.

In 2021-22, 75 case reviews were completed. Key actions arising from case review process included:

- education on:
  - the timing of the completion of the Consulting Assessment
  - when the *Notification of Death form: Coordinating / Administering Practitioner Form* is required to be submitted

- requirements for form submission to the Voluntary Assisted Dying Board within 2 business days
- the sequence for completion and submission of forms relating to the Final Request, Final Review and Administration Decision and Prescription
- appropriate disposal of remaining voluntary assisted dying substance following a practitioner administration
- requirements for Authorised Disposers to submit the Authorised Disposal Form within 2 business days of the disposal occurring
- updates to the Voluntary Assisted Dying Board Monitoring Function Policy
  to monitor submission of an Authorised Disposal Form when a patient has
  died prior to self-administration and the supply of the voluntary assisted
  dying substance has occurred.

#### Referrals

Section 118(c) of the *Voluntary Assisted Dying Act 2019* details the function of the Board to make referrals of matters to other relevant regulatory and investigative bodies:

- Commissioner of Police
- Registrar of Births Deaths and Marriages
- State Coroner
- Chief Executive Officer of the Department of Health
- Chief Executive Officer of the department of the Public Service principally assisting in the administration of the *Prisons Act 1981*
- the Australian Health Practitioner Regulation Agency
- the Director of the Health and Disability Service Complaints Office.

In 2021–22, the Voluntary Assisted Dying Board made one referral to the Chief Executive Officer of the Department of Health relating to the timeliness of an authorised disposal of a voluntary assisted dying substance.

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### Education and research

### **Quality Practice Series**

In 2021–22, the Voluntary Assisted Dying Board supported participating practitioners to enhance their practice through publication of the first edition of the Quality Practice Series which focused on form submission and the use of VAD-IMS. The Quality Practice Series is intended to be a series of tips, reminders and practice points that focus on different areas of the voluntary assisted dying process.

### Research

One of the functions of the Voluntary Assisted Dying Board is to conduct analysis of, and research in relation to, information it receives. Research has been identified as a future focus by the Board.

In 2021–22, the Voluntary Assisted Dying Board participated in the Queensland University of Technology *Enhancing end-of-life decision-making: Optimal Regulation of Voluntary Assisted Dying* research project that aims to enhance end of life care through the design of an optimal holistic regulatory framework.

### Recommendations

Following the first year of implementation of the *Voluntary Assisted Dying Act* 2019, the Voluntary Assisted Dying Board provide the following observations and recommendations.

### **Access to participating practitioners**

In 2021-22, a greater number of voluntary assisted dying requests were received than expected. This has had significant impact on the demand for participating practitioners and statewide services. The Voluntary Assisted Dying Board is concerned about the personal and professional pressures this places on participating practitioners. More participating practitioners are required to meet this greater than expected demand. The Board is aware of strategies implemented by the End-of-Life Care Program to facilitate uptake of the WA VAD Approved Training, including expansion of the Regional Access Support Scheme to remunerate practitioners who support regional residents for completion of the training.

**Recommendation 1:** Develop additional strategies to increase the number of practitioners completing the *WA VAD Approved Training*.

### Impact of the Criminal Code Act 1995 on access to voluntary assisted dying

The *Commonwealth Criminal Code Act 1995* contains offences which limit the use of a carriage service (phone, fax, email, videoconference and internet) to access and transmit suicide-related material. This directly influences how particular parts of the voluntary assisted dying process can be communicated. Electronic communication, information sharing, and the use of telehealth are significant tools in the delivery of health-related services across a state as vast as Western Australia.

The provisions of the *Commonwealth Criminal Code Act 1995* (sections 474.29A and 474.29B), create barriers to providing voluntary assisted dying services that disproportionately impact regional residents. In 2021–22, the Voluntary Assisted Dying Board raised this with the Minister for Health, Attorney General and Chief Executive Officer of the Department of Health.

The Voluntary Assisted Dying Board is aware this issue has been considered by the State and Territory Health Ministers' Meetings and the Health Chief Executives Forums.

**Recommendation 2:** Amendments to the *Commonwealth Criminal Code Act* 1995 to remove the limitations on providing voluntary assisted dying information via a carriage service.

### **Remuneration of practitioners providing services**

In 2021–22, concerns were raised with the Voluntary Assisted Dying Board regarding remuneration for practitioners who provide voluntary assisted dying services. The clinical time and compliance requirements of the voluntary assisted dying process, including submission of forms, is significant.

The Medicare Benefit Schedule item numbers available to remunerate practitioners are insufficient to reasonably account for the time and effort involved. In Western Australia, most participating practitioners choose not to charge voluntary assisted dying patients extra private fees and therefore absorb the costs of providing these services.

The Voluntary Assisted Dying Board has raised this issue with the Minister for Health and Chief Executive Officer of the Department of Health and this matter has been raised with the State and Territory Health Ministers' Meetings and the Health Chief Executives Forums.

**Recommendation 3:** The Medicare Benefit Schedule is reviewed to include the addition of appropriate item numbers to address voluntary assisted dying practitioner remuneration inadequacies.

**Recommendation 4:** The Western Australian Government explore a funding model to support practitioners in performing the administrative processes required to comply with the *Voluntary Assisted Dying Act 2019*, until Australian Government funding mechanisms are amended.

### Support for voluntary assisted dying in the WA health system

The Voluntary Assisted Dying Board recognises the importance of adequate and ongoing funding to support the implementation of the *Voluntary Assisted Dying Act 2019* and access to voluntary assisted dying for eligible Western Australians. This includes resourcing for:

- Voluntary Assisted Dying Board Secretariat Unit
- statewide services including End of Life Care Program, Statewide Pharmacy Service and Statewide Care Navigator Service, including Regional Access Support Scheme
- Health Service Providers to support access to voluntary assisted dying through the provision of program management and clinical leadership.

**Recommendation 5:** Ensure adequate and ongoing funding for the WA health system is provided to support the operation of the *Voluntary Assisted Dying Act 2019*.

### Amendments to the Voluntary Assisted Dying Act 2019

During 2021–22, the Voluntary Assisted Dying Board received feedback from participating practitioners and stakeholders regarding the operation of the voluntary assisted dying process.

**Recommendation 6:** The Voluntary Assisted Dying Board recommends the following sections are considered in the review of the operation and effectiveness of the *Voluntary Assisted Dying Act 2019*:

### Section 77 and 78 Administering Practitioner Disposal Form

The Administering Practitioner Disposal Form is completed by an Administering Practitioner immediately after disposing of a voluntary assisted dying substance. The form currently includes 3 reasons for the disposal (in line with section 77 of the Voluntary Assisted Dying Act 2019):

- · patient revoked practitioner administration decision
- patient died via practitioner administration of voluntary assisted dying substance
- patient died not via practitioner administration of voluntary assisted dying substance.

It is recommended that section 77 and the *Administering Practitioner Disposal Form* are amended to account for additional circumstances in which an administering practitioner may need to dispose of the voluntary assisted dying substance. This may include the patient no longer meeting eligibility criteria or practical reasons such as the substance expiring before it can be administered.

### **Section 162 Interpreters**

The Voluntary Assisted Dying Board is aware concerns have been raised regarding the wording in the *Voluntary Assisted Dying Act 2019* that relates to interpreters, including wording required by the Written Declaration under section 42 which confuses the roles of interpreter and translator. It is recommended that wording in the *Voluntary Assisted Dying Act 2019* should be reviewed and revised as appropriate to clarify and more accurately represent the professional responsibilities of an interpreter engaged for the voluntary assisted dying process.

To increase the number of interpreters who may provide services as part of the voluntary assisted dying process, the Chief Executive Officer of the Department of Health has broadened the bodies that an interpreter may be accredited by under section 163 to also include a Registered Higher Education Provider or a Registered Training Organisation, in addition the National Accreditation Authority for Translators and Interpreters (NAATI).

## Section 58 Self-administration and support to prepare the voluntary assisted dying substance

When a self-administration decision is made, a patient is required to independently prepare the voluntary assisted dying substance. Under the *Voluntary Assisted Dying Act 2019* the patient cannot be assisted with preparing the substance (which includes decanting, mixing etc.) or with the physical act of ingesting the substance. This includes assistance with using their PEG or NG tube.

If the patient is unable to independently undertake these actions or is concerned about their ability to undertake these actions, self-administration is not a suitable option and a practitioner administration decision is made to assist with these actions. It is recommended that section 58 of the *Voluntary Assisted Dying Act 2019* be expanded for the Contact Person or other nominated person to be able to assist the patient in the preparation of the prescribed substance when self-administration is preferred by the patient.

Deaths

### Future focus

In the year ahead, the Voluntary Assisted Dying Board will continue to work closely with the Minister for Health, Chief Executive Officer of the Department of Health, statewide service providers and medical and nurse practitioners to ensure successful implementation of the *Voluntary Assisted Dying Act 2019*.

Areas of focus to support implementation of voluntary assisted dying include:

- on-going review of compliance and monitoring of cases
- advocacy in areas identified in recommendations
- review general and voluntary assisted dying specific grief and bereavement services available in Western Australia and other jurisdictions, including an annual memorial service
- continual review of the Voluntary Assisted Dying Board Monitoring Function Policy
- publication of further editions of the Quality Practice Series
- information and data management:
  - development of governance mechanisms to respond to requests for information in compliance with the provisions in the *Voluntary* Assisted Dying Act 2019
  - commence development of a research strategy
- interjurisdictional engagement and consultation on issues that are common to all states and territories.

# Appendices

## Appendix 1: Disclosures and legal compliance

#### **Financial statements**

In accordance with the *Financial Management Act 2006*, the Department of Health is the accountable authority for the financial management of the Voluntary Assisted Dying Board. The financial activity of the Voluntary Assisted Dying Board, including the remuneration of Board members, is provided within the Department of Health's Annual Report.

#### Section 175ZE of the Electoral Act 1907

Section 175ZE of the *Electoral Act 1907* requires bodies established by a minister to report details of marketing and communications expenditure in their annual reports. The Voluntary Assisted Dying Board did not incur expenditure of this nature in 2021–22.

### **Administrative processes**

The Voluntary Assisted Dying Board Secretariat Unit has been established within the Department of Health under section 121 of the *Voluntary Assisted Dying Act 2019*. As the Department of Health is considered the accountable authority the following items from the Public Sector Commission *Annual Report Guidelines for 2021–22* are included in the Department of Health's 2021–22 Annual Report: occupational safety, health and injury management; WA Multicultural Policy Framework; substantive equality; credit cards; disability access and inclusion plan outcomes and recordkeeping plans.

### Section 155(2) of the Voluntary Assisted Dying Act 2019

Table 14: Section 155(2) of the *Voluntary Assisted Dying Act 2019* requires the inclusion of the following in the Annual Report

Voluntary Assisted Dying Act 2019 section 155(2)		Page reference
(a)	any recommendations that the Board considers appropriate in relation to voluntary assisted dying; and	37–39
(b)	any information that the Board considers relevant to the performance of its functions; and	33–36
(c)	the number of any referrals made by the Board under section 118(c); and	35
(d)	the text of any direction given to the Board under section 123(1) or 152(2); and	34
(e)	details of any disclosure under section 140(1) that relates to a matter dealt with in the report and of any resolution under section 142 in respect of the disclosure; and	34
(f)	statistical information that the Board is directed under section 152(2) to include in the report; and	34
(g)	information about the extent to which regional residents had access to voluntary assisted dying, including statistical information recorded and retained under section 152(1)(c), and having regard to the access standard under section 156.	12, 15, 17, 18, 25, 27, 28, 30, 31

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This document can be made available in alternative formats.

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