# Voluntary Assisted Dying Board Western Australia

Annual Report **2022–23** 

# 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 2023.

**Dr Scott Blackwell** 

Chairperson, Voluntary Assisted Dying Board

New Harbure

8 November 2023

# Contents

Ovei	rview	2
	About this report	2
	Foreword	3
	Year in review	6
	Personal reflections	7
Heal	th practitioners	13
	Health practitioner participation	13
Volu	ntary assisted dying process	16
	Access to voluntary assisted dying	16
	First Request	17
	First Assessment	19
	Consultation Assessment	26
	Final Request and Final Review	27
	Administration Decision	28
	Supply of the voluntary assisted dying substance	29
Deat	ths	31
	Voluntary assisted dying deaths	31

lmpl	ementation	39
	Notifications to the Voluntary Assisted Dying Board	39
	Statewide services to support voluntary assisted dying	42
Volu	ntary Assisted Dying Board	47
	Voluntary Assisted Dying Board	47
	Monitoring	50
	Education, data and research	51
	Stakeholder engagement	52
	Recommendations	53
	Future focus	58
App	endices	59
	Appendix 1: Disclosures and legal compliance	59
	Appendix 2: Key contact list	60
	Appendix 3: List of tables and figures	61
	Appendix 4: Voluntary assisted dying proposed national minimum dataset 2022–23 Western Australia	62

# 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 to 30 June 2023.

#### 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 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 29 August 2023 to account for activity that occurred up to 30 June 2023. Footnotes are included throughout the report to assist with interpretation of the data. Figures have been rounded to one decimal place and, due to rounding, totals may exceed 100 per cent. Patients may undertake the same process step in different time periods, so the sum of the number of patients undertaking an activity each year may exceed the all-time count. This report also contains minor revisions to the 2021–22 data where new information was received or updated. 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 and patients with no fixed address.

Contents

## **Foreword**

I am pleased to present the second annual report of the Voluntary Assisted Dying Board (the Board).

On behalf of the Board, I express condolences to all the family and friends of those who made the choice of voluntary assisted dying and have died in 2022–23. We recognise your loss and wish you well as you grieve. We also thank those who have shared their experience of voluntary assisted dying with the Board. You have helped keep our work person-centred.

#### **Functions of the Board**

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

In 2022–23, the Board developed policies to guide the performance of functions related to data provision and research. The Board will focus on improving information provision and pursuing research projects that contribute to the understanding of voluntary assisted dying in the coming year.



Front (left to right): Ms Maria Osman, Ms Linda Savage. Back (left to right): Dr Robert Edis, Dr Scott Blackwell, Mr Colin Holt.

#### **The second Annual Report**

The Annual Report 2022–23 provides the opportunity to present data that illustrates that voluntary assisted dying is now established as a consistent choice for Western Australians at the end of their lives.

The introduction of voluntary assisted dying laws was driven by the Western Australian community. The resulting Act has proven to be effective legislation and ensured the voluntary assisted dying process has been safe and accessible. In the first 2 years of the Act, 1,120 people have requested voluntary assisted dying leading to 446 people exercising their choice to die by voluntary assisted dying.

This report also allows us to reflect on the data and the highly personal, occasionally sensitive, matters that have been brought to the Board's attention as it carries out its role of examining ways in which voluntary assisted dying can be improved in Western Australia.

The Board was pleased to see that the number of health practitioners that have completed the training requirements for voluntary assisted dying has increased over the year, including several nurse practitioners. This has resulted in more health practitioners being available to provide services to those who choose voluntary assisted dying. However, there is still a need for more health practitioners to take up the training and become active in the service of voluntary assisted dying. Ongoing effort will be required to ensure that a sufficient practitioner pool is available to respond to the level of requests from the community and avoid practitioner burnout and fatigue. Amending the Act to permit nurse practitioners to fulfill more roles in the process could assist in meeting this need and improve the experience of practitioners and patients through the process.

Health practitioner availability is vital to the successful provision of voluntary assisted dying services to Western Australians, and it is of ongoing concern to the Board that there is still no secure funding for their services. Practitioners deserve to be adequately remunerated for the extensive time they spend assessing and supporting patients through the voluntary assisted dying process and for the mandatory administrative and reporting activities involved. To date most participating practitioners have absorbed the costs of providing these services where Medicare Benefit Schedule item numbers available to remunerate practitioners are insufficient to reasonably account for the time and effort involved. In 2022–23, the Board has become increasingly aware of voluntary assisted dying being provided as a private fee for service model. Practitioner remuneration and ongoing support for voluntary assisted dying within the WA Health system should be addressed as a matter of priority.

The principles of the Act include that a person is entitled to genuine choices about care and treatment at the end of their life. It is disappointing that in 2022–23, the Board has been made aware of instances where individuals or organisations have obstructed Western Australians who have sought access to voluntary assisted dying. The Board recommends that the Act is amended at the earliest opportunity to ensure patients and residents of health service facilities are not prevented from accessing voluntary assisted dying as a lawful end of life choice.

In 2022–23, South Australia, Tasmania and Queensland joined Victoria and Western Australia in implementing voluntary assisted dying as an end-of-life choice, with New South Wales to follow in November 2023. As voluntary assisted dying becomes available across Australia, there is an opportunity to consider a more contemporary approach to residency criteria that aligns with community sentiment around access to voluntary assisted dying. The Board recommends the Act is amended to provide access for long-term Australian residents, those with a substantial connection to Western Australia or those who have been found eligible in another jurisdiction.

Patients, statewide service providers, and participating practitioners continue to encounter barriers to voluntary assisted dying that arise from the provisions of the *Commonwealth Criminal Code Act 1995* (the Code). The expansion of the Regional Access Support Scheme has been welcomed as a positive development in 2022–23 however, this does not overcome the impacts of the Code, particularly on regional residents. The Board shares the concerns raised by voluntary assisted dying review boards in other Australian jurisdictions and reiterates its recommendation that the Code is amended expeditiously.

The Board has become increasingly aware of the shift from self-administration to practitioner administration during the second year. It has become clear to the Board that the provision in the Act that requires the person to prepare and take the substance themselves, without assistance, is a disincentive to self-administration. While the intent of the legislators was to protect the person, this provision has in practice acted as a disincentive to their choice for self-administration. To provide a more acceptable choice for self-administration, in 2021–22 the Board recommended that this be considered as part of the review of the operation and effectiveness of the Act<sup>1</sup>.

The Board also makes recommendations regarding public education, grief and bereavement support and other matters for consideration in the review of the Act and for improving the operation of voluntary assisted dying later in this report.

<sup>1</sup> Voluntary Assisted Dying Board Annual Report 2021–22

#### Thank you

We recognise that from the moment we are born, we become a part of a family and a community, and when we die, we leave from that family and community. Our lives are intertwined with those of others; it's not solely about one individual. The Board appreciates the respect shown to those who choose voluntary assisted dying at the end of their life. We are grateful to the dedicated participating practitioners, the care navigators and the pharmacists who contribute beyond the normal call of duty. Your service, which makes voluntary assisted dying possible and safe, is highly valued by the Board. Its significance goes far beyond that of the data presented in this report. We thank you for the exceptional work that you do.

The vastness of Western Australia presents its own challenges, and the Board understand the need to gain insight into the issues that arise with the provision of voluntary assisted dying services statewide. In 2022–23, we have commenced a program of regional visits to enhance our understanding of the unique regional requirements. We are grateful to the people of the Great Southern region, particularly Albany, for their hospitality during our first regional visit. We were impressed at the way you capitalise on the strength of your community spirit, as exemplified by Albany Community Hospice's patient-centred care.

The Board is thankful for the support of the Director General, Dr D J Russell-Weisz and recognises the good work done by the End of Life Care Program team in the Department of Health. Our partnership enables us to keep the provision of voluntary assisted dying on course in Western Australia.

During 2022–23 the Board has been expertly supported by a dedicated Secretariat Unit who carry out their duties to a very high standard. The work of the Board is often complex and demanding and we are grateful not only for the professionalism you demonstrate in your work, but also for the environment you maintain that supports us in what we seek to achieve.

We remain committed to maintaining the integrity and reputation of voluntary assisted dying in Western Australia and express our gratitude to the Minister for Health, the Hon Amber-Jade Sanderson, for her enduring support of voluntary assisted dying throughout 2022–23.

**Dr Scott Blackwell** 

Chairperson

Voluntary Assisted Dying Board

New Harbur

# Year in review

Voluntary assisted dying in 2022–23 (including change from 2021–22)

**First Requests** 

7 4.3%

**First Assessments** 

474 23.4%

**Consulting Assessments** 

397 22.5%

Substance supplies

283 19.4%

Voluntary assisted dying deaths

255 33.5%

Patients found eligible to access voluntary assisted dying

Age

30 - 99

Median age

74

Male

58.8%

**Female** 

41.2%

Resided in metro area

75.6%

Resided in regional area

24.4%

Cancer related diagnosis

73%

Receiving palliative care

86%

Voluntary assisted dying deaths

**Self-administration** 

45 (17.6%)

Practitioner administration

210 (82.4%)

45.7% of practitioner administration occurred at the patients home

79% of practitioner administration via intravenous administration

1.4% of total deaths in Western Australia

in 2022-23

Voluntary assisted dying deaths

Trained practitioners

97

Training completed in 2022–23

20 Medical practitioners

7 Nurse practitioners

Location of practice

71.1% Perth metro 28.9% Regional

Participated since 1 July 2021

68 Medical practitioners

Nurse practitioner

## Personal reflections

The Voluntary Assisted Dying Board (the Board) receives feedback via personal reflections from those involved in the voluntary assisted dying process, including the patient, their family or practitioners who are part of their care. The Board is very appreciative for the contribution of personal reflections in 2022–23, which assisted the Board's understanding of voluntary assisted dying in Western Australia. The consideration of personal reflections throughout the year enabled the Board to share a number of recommendations with statewide services to improve the safety and quality of voluntary assisted dying.

Key themes expressed in personal reflections include:

- appreciation for the care, understanding and respect displayed by participating practitioners, care navigators, pharmacy service, health service provider coordinators and treating teams throughout the voluntary assisted dying process
- gratitude for the autonomy of voluntary assisted dying as an end-of-life choice
- the impact of voluntary assisted dying on grief and bereavement
- family experiences at time of administration of voluntary assisted dying substances
- barriers to making a First Request with a participating practitioner
- barriers to accessing voluntary assisted dying at private facilities
- eligibility to access voluntary assisted dying.

To protect the privacy of individuals, personal reflections have been deidentified. We acknowledge the following personal reflections may be distressing to some readers.

Appreciation for the care, understanding and respect displayed by participating practitioners, care navigators, pharmacy service, health service provider coordinators and treating teams throughout the voluntary assisted dying process

'We would like to say that we could not speak highly enough of the entire process. [Coordinating Practitioner] was absolutely amazing, so caring, explained the process perfectly and made us all feel at ease. His bed side manner was incredible and very professional....[Care Navigator] was a constant support. She called us many times to check in on us and made the process easy. Everything was explained perfectly and we all felt that mum's decision was not only the right one but one we all felt at peace with.' Family member

'I am writing to express my heartfelt thanks and my sincere gratitude to all the wonderful and caring people associated with [voluntary assisted dying]. Your dedication to helping people achieve a dignified and peaceful end of life experience is truly commendable.'

Family member

...we were greeted by sympathy and kindness at every stage. From the first person to come for the introduction, to the two wonderful doctors who did a consult with my mother to ascertain her position, to the pharmacists who made the delivery of the drugs, my mother was treated with great respect and understanding."

Family member

"... I have absolute admiration for both [Health Service Provider Voluntary Assisted Dying Coordinator] and [Coordinating Practitioner] for not only the professionalism, but the gentleness and willingness to discuss all the options without a time limit placed on our meeting."

Family member

#### Gratitude for the autonomy of voluntary assisted dying as an end-of-life choice

'We will always be very thankful that there was a pathway for mum to access [voluntary assisted dying] as she said it was her time to go. The assessment and request process was completed in a very timely, sympathetic and supportive manner. At all times it was emphasised that it was mum's choice only if and when she wished to proceed.'

Family member

"...Dad decided that he wanted to be able to choose when he went, and not to let this disease completely strip him of any dignity. He wanted to go, 'his way' and when he wanted to go. He picked a date. He had several of his closest friends and family around him and we celebrated his life with stories of love and thanks."

Family member

'I am extremely grateful that we in Western Australia are able to access [voluntary assisted dying]. I saw firsthand how compassionate and empowering the gift of a peaceful end-of-life can be.'

Friend of patient

'The most important point I want to make is to express my sincere gratitude to the WA Government and Parliament for getting the [voluntary assisted dying] legislation through against significant opposition. I am now qualified and to know that this is available is very reassuring, even if I don't use it.'

Patient

'I would like to acknowledge the wisdom, knowledge, hard work and passion that has made [voluntary assisted dying] possible. These were people facing their own death, their families, organisation and institutions who lobbied, created and continue to support this option, enabling practitioners like myself who are called to perform this role.'

Participating practitioner

#### The impact of voluntary assisted dying on grief and bereavement

'My personal experience of the lead up to my friend's [voluntary assisted dying death] was a bit of a roller coaster. I felt privileged to be involved but then dreaded the actual day; grief that I would be losing a confidante and gratitude for her friendship; doubt that it was the right decision and admiration for her courage; strong and supportive one day and weak and inadequate the next. As I learned after my friend's death, these feelings were all natural and necessary. On the day, I saw that she was profoundly peaceful and had great faith in the 'rightness' of her decision. I left feeling uplifted.' Friend of patient

'My father's wishes were to end his life as soon as he was no longer able to look after himself without help from family and medical staff. This was very confronting for me as I was torn between trying to help him and then make the call to end his life, the [Care Navigator] was very helpful and understanding, it took me awhile to come to terms with this.'

Family member

'I advised [Health Service Provider Voluntary Assisted Dying Coordinator] of [Patient] passing and she got back to me via email with options of how we could deal with our grief and loss of our son.'

Family member

'The difficult part for me was I lost my dad on that day. I understand that it was 'for the best' but I felt that the system lacked the emotion for those left behind. There was no counselling offered at the time which would have been invaluable to me. Nearly 12 months later I am still struggling with the loss but I am ultimately thankful that his illness did not progress to the point of him losing his dignity."

Family member

'We cried together, unsure what we needed to do for him. We felt very lost. The procedure was exactly as we had been told, but there was no procedure for what to do next."

Family member

'In retrospect, I would like to have had the option of a death doula to help us navigate those peri and post death times. Despite us all being a very pragmatic, loving and informed family, the shock of that final moment when you know that the soul is gone and the vehicle is all that remains is guite profound. I am not sure that such assistance would suit everybody, but from what I know now I would like to have had the option, paid or not.'

Family member

**Implementation** 

#### Family experiences at time of administration of voluntary assisted dying substances

'The day of mum's passing became an incredible day. [Coordinating Practitioner] and [Care Navigator] were truly exceptional. They gave us all the time we needed to say our goodbyes. They carried out the process in such a caring and professional manner. We were all so impressed to the point that we felt relieved that mum got to leave us completely pain free and in peace. We have never seen such a devastating situation be so peaceful.' Family member

'Mum was suffering from bowel cancer and had been on extreme minimal fluid and no food for a full week. This made accessing veins suitable in her arm extremely difficult, not just once but in both arms. Her family surrounding her were distressed at seeing how difficult this process was. Mum meantime assuring all that it was fine, she was 'ok'. Whether the canula's could be inserted earlier to remove extreme pressure on doctors and stress on patient and witness.'

Family member

'She died peacefully, as she had wanted and had been promised, my brother and I holding her good hand, with her family beside her. It was a remarkable but calm end to her long life and was amazing to see her push for this opportunity at her age."

Family member

#### Barriers to making a First Request with a participating practitioner

'We made a GP appointment, but [patient's] doctor wasn't trained and didn't know how to start the process either.'

Family member

'It was so obvious. I asked 4 times. I think they have a problem with that. Nobody made any positive moves to help me while I was there...I just felt that I was being very gently ignored."

**Patient** 

'Several days after arriving we were told on the day before the New Year long weekend she had requested to die by [voluntary assisted dying] and the registrar had recorded her wishes, provided her with the written information about [voluntary assisted dying] and notified [the Board]...It is worth noting that some family members, including [Patient], believed the process started with her request to the registrar and that nothing more needed to be done the process they believed was now initiated.'

Family member

'I felt extremely disappointed to have a medical practitioner delay a patients access to [voluntary assisted dying]..... Resulting in unnecessary delays to [voluntary assisted dying] in which the patient has a right to access." Nurse

#### Barriers to accessing voluntary assisted dying at private facilities

'When we initiated the process what caught me most by surprise was that if my mother had had to go to certain medical care facilities we wouldn't have been able to engage in any [voluntary assisted dying] discussions on the premises. Considering her extreme lack of mobility in those final days (which would have made any trip outside very difficult), I was thankful she was able to stay at home till the last moment. I think this should be made clear in advance for patients in the future so they can prepare alternative courses of action.'

Family member

'After I made my first request through the [Statewide Care Navigator Service], I was given the [Approved information for a person making a First Request for voluntary assisted dying booklet] which I read in detail and found very helpful. The problem is that it completely ignores the elephant in the room, being the whole [name of private health service facility] is completely opposed to [voluntary assisted dying] and will not allow any part of the process in their premises....They state that they welcome all patients and caregivers, respecting their views and beliefs. Well.....no they don't.... They claim that significant discomfort at end of life is rare, but that acknowledges that it occurs, and they still won't allow [voluntary assisted dying].'

#### Eligibility to access voluntary assisted dying

'The day prior to his scheduled [voluntary assisted dying] administration, his breathlessness became so distressing that he was given larger doses of midazolam and morphine that resulted in symptom relief, with loss of capacity, and death with palliative sedation. I met with his son weeks after his death and on reflection, he was disappointed that his father had been unable to exit this life with a clear mind. The son found the long night of declining respiratory effort with periods of what looked like breathing distress, in his semi-conscious father, difficult to witness.'

Participating practitioner

'The need for mental capacity to the last second seems incongruent with a previously clearly declared decision to seek relief via [voluntary assisted dying] when pain relief medication may be interfering with the capacity to give informed consent in the last moment. Further, on mental capacity,... we are watching our mother deteriorate but due to her dementia know that no matter how bad her life becomes she cannot be allowed a dignified and peaceful release from life.'

Family member

'Although he had been an avid reader all his life, he could no longer read. He struggled to make himself understood on the phone and in conversations. There was just no quality of life remaining. Living was no longer bearable for [Patient]. There can be no doubt that the law in its current state, failed [Patient], his family and the community. I respectfully request that consideration be given to amending the law to make it more widely accessible, particularly where it is clear that the applicant will suicide if consent is not given.'

Friend of patient

12

# 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.

A total of 97 medical and nurse practitioners have completed the WA VAD Approved Training (90 medical practitioners, 7 nurse practitioners), with 20 medical practitioners and 7 nurse practitioners completing the training in 2022–23.

Since 1 July 2021, 68 medical practitioners (70.1% of participating practitioners<sup>2</sup>) acted as a Coordinating, Consulting or Administering Practitioner<sup>3</sup>, with 18 medical practitioners acting in a role for the first time in 2022–23. Nine medical practitioners who acted as a Coordinating, Consulting or Administering practitioner in 2021–22 did not act in a role in 2022–23. One nurse practitioner acted as an Administering Practitioner in 2022–23.

<sup>2</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.

<sup>3</sup> A participating practitioner is considered to have acted in the role of a Coordinating, Consulting or Administering Practitioner through the submission of a First Assessment, Consulting Assessment or Practitioner Administration Form.

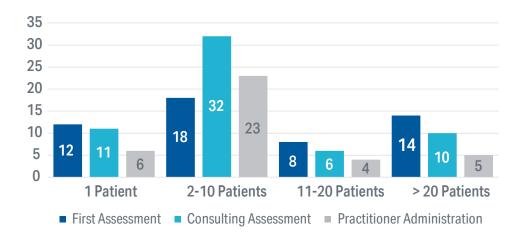
Since 1 July 2021, participating practitioners are most likely to have acted as a Coordinating, Consulting or Administering Practitioner for between 2 to 10 patients.

More than half of participating medical practitioners have completed at least one First Assessment as a Coordinating Practitioner (n=52, 57.8%). Of these, 76.9 per cent (n=40) completed more than one First Assessment and 42.3 per cent (n=22) 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=784, 91.4%).

Participating medical practitioners were most likely to have completed a Consulting Assessment with 65.6 per cent (n=59) completing at least one Consulting Assessment since 1 July 2021.

More than a third of participating medical and nurse practitioners have acted as an Administering Practitioner since 1 July 2021 (n=38, 39.2%).

Figure 1: Number of practitioners who completed a First Assessment, Consulting Assessment and Practitioner Administration 2021 to 2023



#### **Location of practice**

Participating practitioners nominated a practice address<sup>4</sup> across all regions except the Wheatbelt. More than two thirds of participating practitioners were based in the Perth metropolitan region (n=69, 71.1%).

Table 1: Number of participating practitioners by health region 2021 to 2023

Region of practice	Total	% of total
Perth metropolitan	69	71.1%
Goldfields	1	1.0%
Great Southern	6	6.2%
Kimberley	5	5.2%
Midwest	2	2.1%
Pilbara	2	2.1%
South West	12	12.4%
Wheatbelt	0	0.0%
Total	97	100.0%

<sup>4</sup> Medical Practitioners nominate their work address when registering to use VAD-IMS.

#### **Practitioner specialty**

Participating medical practitioners hold registration with a range of specialties<sup>5</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. General practice was the specialty of 44.6 per cent (n=45) of participating practitioners.

5 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.

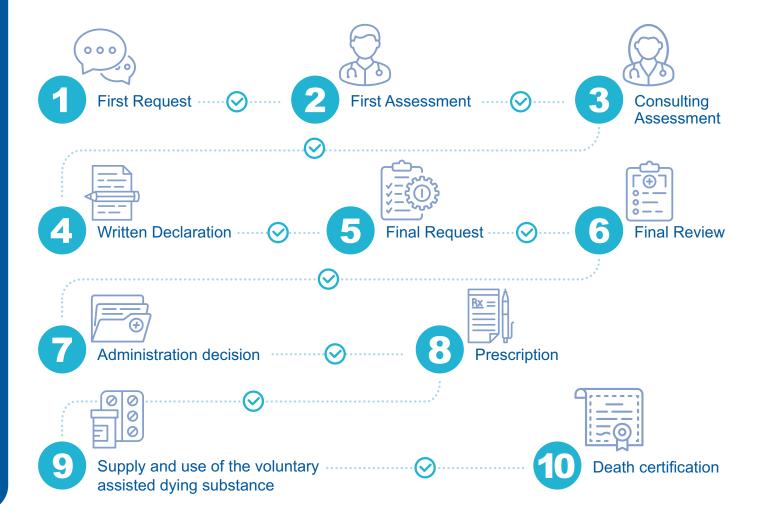
Table 2: Number of participating practitioners by specialty type 2021 to 2023

Participating practitioner specialty	Total	% of total
General practice	45	44.6%
Psychiatry	8	7.9%
Nurse practitioner	7	6.9%
Anaesthesia	7	6.9%
Emergency medicine	6	5.9%
Haematology	5	5.0%
Neurology	4	4.0%
Medical oncology	4	4.0%
Geriatrics	3	3.0%
Palliative care	2	2.0%
Paediatrics and child health	2	2.0%
Clinical pharmacology	1	1.0%
General medicine	1	1.0%
General registration only	1	1.0%
Intensive care medicine	1	1.0%
Obstetrics and gynaecology	1	1.0%
Pain medicine	1	1.0%
Physician	1	1.0%
Rheumatology	1	1.0%
Total	101	100.0%

# Voluntary assisted dying 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, they may recommence the request and assessment process by making a new First Request.



# First Request

A person starts the voluntary assisted dying process by making a clear and unambiguous request for voluntary assisted dying to a medical practitioner during a medical consultation, known as a First Request. Medical practitioners must notify the Board when they receive a First Request and advise if the First Request is accepted or refused.

Acceptance or refusal of a First Request relates to whether the practitioner is willing, able and eligible to take on the role of Coordinating Practitioner in the voluntary assisted dying process. Once a medical practitioner accepts a First Request, they become the person's Coordinating Practitioner.

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.

Since the commencement of the Act on 1 July 2021 1,120 people have made a First Request to access voluntary assisted dying. In 2022–23:

- 608 people made a First Request to access voluntary assisted dying, an increase of 14.1 per cent over the number of people who made a First Request in 2021–22 (n=533). Of these:
  - 432 people (71.1%) made only one First Request, of which 325 (75.2%) were accepted and 107 (24.8%) were refused
  - 176 people (28.9%) made more than one First Request
- 757 First Requests were made as some people made more than one First Request<sup>6</sup>. Of these:
  - 66.6 per cent of First Requests were accepted (n=504), an increase from 57.9 per cent in 2021–22 (n=420)
  - 33.4 per cent of First Requests were refused (n=253), a decrease from 42.1 per cent in 2021–22 (n=306).

<sup>6</sup> Information is provided based on a First Request being made and a First Request Form being submitted to the Voluntary Assisted Dying Board.

A practitioner being ineligible to participate in the voluntary assisted dying process was the most common reason a First Request was refused in 2022–23 (n=98, 38.7%). Conscientious objection to voluntary assisted dying was recorded as the reason in 15 per cent (n=38) of First Requests that were refused.

In 2022–23, First Requests were made by persons residing in each region of Western Australia, with 74.2 per cent (n=562) of First Requests made by persons in the Perth metropolitan region. The number of reported First Requests from persons residing in regional areas increased by 14 per cent from the previous year, with increased requests from the Kimberley, Midwest, Pilbara, South West and Wheatbelt regions.

Table 3: Number of First Requests made by health region in 2021–22 and 2022–23

Health Region	2021–22	2022-23	Total	% of total
Perth metropolitan	555	562	1,117	75.3%
Goldfields	14	11	25	1.7%
Great Southern	63	58	121	8.2%
Kimberley	7	10	17	1.1%
Midwest	16	20	36	2.4%
Pilbara	6	7	13	0.9%
South West	47	63	110	7.4%
Wheatbelt	18	26	44	3.0%
Total	726	757	1,483	100.0%

18 Contents Overview Health practitioners Voluntary assisted dying process Deaths Implementation Voluntary Assisted Dying Board Appendices

## 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.

Since 1 July 2021, 841 patients have completed a First Assessment to assess eligibility for voluntary assisted dying, with 465 patients assessed in 2022–23. This represents an increase of 23.7 per cent over the number of patients who completed a First Assessment in 2021–22 (n=376).

In 2022–23, 474 First Assessments were completed as some patients had more than one First Assessment<sup>7</sup>. Of the First Assessments completed in 2022–23:

- 89 per cent of assessments (n=422) had an eligible outcome, a decrease from 92.2 per cent (n=354) in 2021–22
- 11 per cent of assessments (n=52) had an ineligible outcome, an increase from 7.8 per cent (n=30) in 2021–22.

#### **Eligibility**

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.

If a patient does not meet the eligibility criteria, they are assessed as ineligible, and the voluntary assisted dying process stops.

Contents

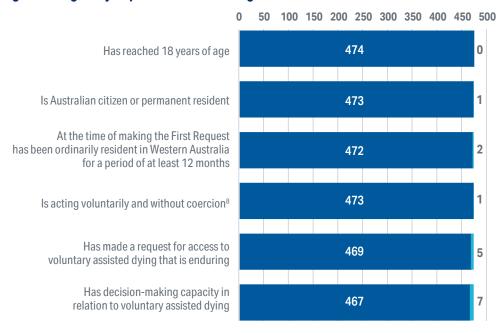
<sup>7</sup> A patient may have completed more than one First Assessment. Scenarios include:

<sup>•</sup> 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

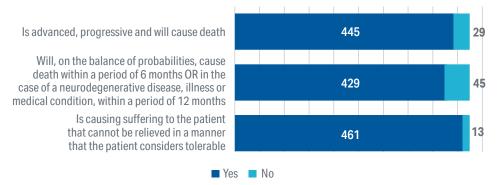
if a patient withdrew from the request and assessment process and then at a subsequent date made a new First Request.

In 2022–23, 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 (n=45).

Figure 2: Eligibility of patients undertaking First Assessment in 2022–23



Has been diagnosed with at least 1 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.

A referral for determination was completed as part of 25 First Assessments in 2022–23, with 28 referrals made as two patients were referred for more than one eligibility criteria. This represents 5.3 per cent of all First Assessments, an increase from 2.3 per cent in 2021–22 (n=9). The majority of referrals (n=25) were made regarding the patient's disease, illness or medical condition.

20 Contents Overview Health practitioners Voluntary assisted dying process Deaths Implementation Voluntary Assisted Dying Board Appendices

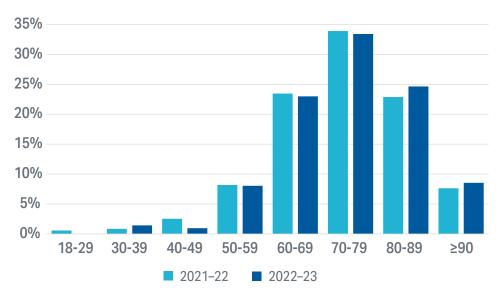
<sup>8</sup> Coordinating Practitioner confirmed that they were unable to confirm eligibility against this criteria (acting voluntarily and without coercion) due to the patient's acute delirium.

# Profile of eligible patients requesting access to voluntary assisted dying

There were 422 patients assessed as eligible to access voluntary assisted dying after the completion of a First Assessment in 2022–23, bringing the total number of eligible patients to 776 since 1 July 2021.

In 2022–23, eligible patients were aged 30 to 99 years, with a median age of 74.

Figure 3: Distribution of patient age at First Assessment in 2021–22 and 2022–23



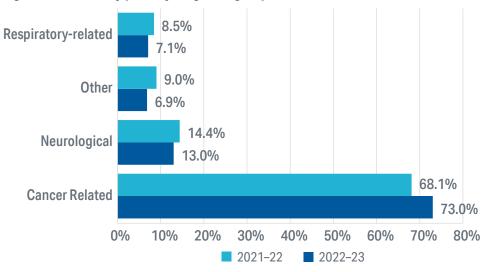
#### In 2022-23:

- a greater proportion of eligible patients were male (58.8%) than female (41.2%)
- approximately three quarters of patients assessed as eligible resided in the Perth metropolitan region (n=319, 75.6%), a decrease from 78.5 per cent in 2021–22
- 1.4 per cent of patients assessed as eligible were of Aboriginal origin (n=6), a decrease from 2.0 per cent in 2021–22
- more than a third of patients assessed as eligible were born overseas (n=161, 38.2%), a decrease from 41.5 per cent in 2021–22
- 7.1 per cent of eligible patients did not identify English to be their first language (n=30), a decrease from 9.9 per cent in 2021–22
- patients assessed as eligible were most likely to report being in a married or de-facto relationship at the time of First Assessment (n=191, 45.3%)
- two thirds of patients assessed as eligible reported living with family or others at the time of First Assessment (n=280, 66.4%)
- patients assessed as eligible most commonly reported high school as their highest level of education (n=191, 45.3%).

#### **Primary diagnosis**

The majority of patients found eligible at First Assessment had a cancer-related primary diagnosis (n=308, 73.0%), an increase from 68.1 per cent in 2021–22 (n=241). 'Other' diagnoses included congestive heart failure, end stage renal failure and peripheral vascular disease.

Figure 4: Patients by primary diagnosis group in 2021–22 and 2022–23



#### In 2022-23:

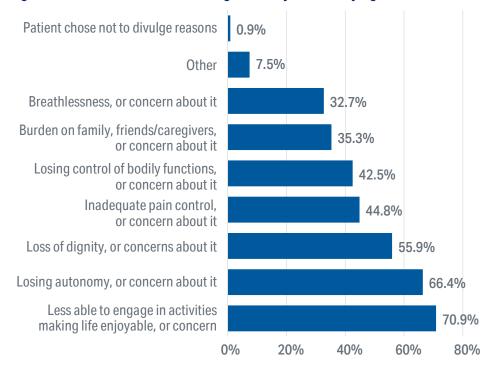
- the most common primary diagnosis in men and women was lung cancer
- the most common cancers were cancers of the lung (n=67), colorectal (n=25), pancreas (n=23) and prostate (n=23)
- the most common neurological diagnoses were motor neurone disease (n=33), progressive supranuclear palsy (n=5) and multiple system atrophy (n=3)
- the most common respiratory related diagnoses were chronic obstructive pulmonary disease (n=8), interstitial lung disease (n=8) and end stage chronic obstructive airways disease (n=5).

#### 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 2022–23, 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 (70.6%) followed by losing autonomy, or concern about it (66.4%). These results are similar to 2021–22.

Figure 5: Patient reason for accessing voluntary assisted dying 2022–23



**Implementation** 

#### **Palliative care**

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 2022–23, most patients assessed as eligible were receiving palliative care at the time of the First Assessment (86.0%), a slight increase from 2021–22 (85.3%). Patients were most commonly receiving community or home-based palliative care at the time of the First Assessment (47.9%). Whilst this remains the most common type of palliative care received, this represents a decrease from 56.6 per cent in 2021–22.

Table 4: Palliative care information collected during First Assessment in 2021–22 and 2022–23°

Patients receiving palliative care at time of First Assessment		2021–22	2022–23	Total	% of total	
No	No		52	59	111	14.3%
If no, have th	•	No	43	50	93	83.8%
within last 12	2 months?	Yes	9	9	18	16.2%
Yes			302	363	665	85.7%
	Community home-base palliative c	d	171	174	345	51.9%
	Specialist palliative c	are unit	63	65	128	19.2%
If yes, from	General practitione	r	58	72	130	19.5%
where?	Consultation a hospital	on in	55	99	154	23.2%
	Outpatient	clinic	23	44	67	10.1%
	Consultation a facility	on in	12	13	25	3.8%
Total			354	422	776	100.0%

<sup>9</sup> For patients currently receiving palliative care, more than one care type can be recorded.

Table 5: Demographic characteristics of patients assessed as eligible for voluntary assisted dying in 2021–22 and 2022–23

Characteristic	2021–22	2022-23	Total	% of total		
Patient age						
18-29	2	0	2	0.3%		
30-39	3	6	9	1.2%		
40-49	9	4	13	1.7%		
50-59	29	34	63	8.1%		
60-69	83	97	180	23.2%		
70-79	120	141	261	33.6%		
80-89	81	104	185	23.8%		
≥90	27	36	63	8.1%		
Patient region						
Metropolitan	278	319	597	76.9%		
Goldfields	8	3	11	1.4%		
Great Southern	22	31	53	6.8%		
Kimberley	4	5	9	1.2%		
Midwest	8	13	21	2.7%		
Pilbara	3	3	6	0.8%		
South West	19	33	52	6.7%		
Wheatbelt	12	15	27	3.5%		

Characteristic	2021–22	2022-23	Total	% of total		
Gender						
Male	205	248	453	58.4%		
Female	149	174	323	41.6%		
Other	0	0	0	0.0%		
Aboriginal or Torres S	trait Islander (	origin				
No	347	416	763	98.3%		
Aboriginal	7	6	13	1.7%		
Torres Strait Islander	0	0	0	0.0%		
Aboriginal and Torres Strait Islander	0	0	0	0.0%		
Born overseas						
No	207	261	468	60.3%		
Yes	147	161	308	39.7%		
English first language						
No	35	30	65	8.4%		
Yes	319	392	711	91.6%		
How well does the pat	ient speak En	glish				
Not at all	2	2	4	0.5%		
Not well	1	5	6	0.8%		
Well	16	17	33	4.3%		
Very well	335	398	733	94.5%		

Characteristic	2021–22	2022-23	Total	% of total		
Patient ancestry						
Australian	151	177	328	42.3%		
Chinese	3	5	8	1.0%		
Dutch	13	9	22	2.8%		
English	107	132	239	30.8%		
German	8	14	22	2.8%		
Indian	7	4	11	1.4%		
Irish	11	15	26	3.4%		
Italian	11	7	18	2.3%		
New Zealand	5	5	10	1.3%		
Other	27	32	59	7.6%		
Scottish	11	22	33	4.3%		
Assisted by interprete	r during First	Assessment				
No	352	417	769	99.1%		
Yes	2	5	7	0.9%		
Usual living circumstances						
Lives with family	215	251	466	60.1%		
Lives alone	115	142	257	33.1%		
Lives with others	24	29	53	6.8%		

Characteristic	2021–22	2022-23	Total	% of total		
Relationship status						
Divorced	60	79	139	17.9%		
Married/De facto	176	191	367	47.3%		
Never married	29	44	73	9.4%		
Separated	17	13	30	3.9%		
Widowed	71	95	166	21.4%		
Not reported	1	0	1	0.1%		
Highest level of educa	tion					
Primary school	10	14	24	3.1%		
High school	138	191	329	42.4%		
Year 12 graduation	51	37	88	11.3%		
Trade certificate	42	73	115	14.8%		
Advanced diploma and diploma	38	30	68	8.8%		
Bachelor degree	49	46	95	12.2%		
Postgraduate degree	26	30	56	7.2%		
Not reported	0	1	1	0.1%		
Diagnostic group				'		
Cancer related	241	308	549	70.7%		
Neurological	51	55	106	13.7%		
Other	32	29	61	7.9%		
Respiratory related	30	30	60	7.7%		

## 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.

Since 1 July 2021, 713 patients have completed a Consulting Assessment, with 394 patients assessed in 2022–23. This represents an increase of 22.7 per cent over the number of patients who completed a Consulting Assessment in 2021–22 (n=321).

In 2022–23, 397 Consulting Assessments were completed as some patients had more than one Consulting Assessment<sup>10</sup>. Of the Consulting Assessments completed in 2022–23:

- 98.7 per cent of assessments (n=392) had an eligible outcome, this is similar to 2021–22 (98.8%, n=320)
- 1.3 per cent of assessments (n=5) had an ineligible outcome, this is similar to 2021–22 (1.2%, n=4).

A referral for determination was completed as part of 2 Consulting Assessments in 2022–23, with 3 referrals made as one patient was referred for more than one eligibility criteria.

<sup>10</sup> The data includes forms with a status of valid and void.

# Final Request and Final Review

#### **Final Request**

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* (the Act) 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.

Since 1 July 2021, 631 patients made a Final Request to access voluntary assisted dying and 20.9 per cent (n=132) of these patients made the Final Request within the 9-day designated period. The median number of days between First Request to Final Request was 13 days.

Of the patients who made a Final Request, 77 per cent resided in the Perth metropolitan region (n=486) and 23 per cent resided in regional areas (n=145). Regional patients were more likely to make a Final Request within the 9-day designated period (24.8%) than patients residing in the Perth metropolitan area (19.8%).

#### In 2022-23:

- 347 patients submitted a Final Request, an increase of 22.2 per cent from 2021–22 (n=284)
- 23.9 per cent of patients (n=83) made the Final Request within the 9-day designated period, an increase from 17.3 per cent in 2021–22 (n=49).
   Of these:

- 45.8 per cent (n=38) 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, representing an increase from 40.8 per cent in 2021–22 (n=20)
- 54.2 per cent (n=45) 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, representing a decrease from 59.2 per cent in 2021–22 (n=29).

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

#### **Final Review**

The request and assessment process concludes with the Final Review. The Coordinating Practitioner completes a Final Review to ensure that the voluntary assisted dying request and assessment process has been completed in accordance with the Act. As part of the Final Review, the Coordinating Practitioner must make sure that the patient has decision making capacity in relation to voluntary assisted dying, is acting voluntarily and without coercion, and still wants to access voluntary assisted dying. Since 1 July 2021, 631 patients have completed the Final Review, with 347 patients reviewed in 2022–23. At the time of Final Review, one patient was found to be ineligible and access to voluntary assisted dying was unable to proceed as the practitioner was unable to certify that the patient had decision making capacity, was acting voluntarily and without coercion and that the request to access was enduring.

#### Patients who withdrew

**Implementation** 

Further to the patients who died prior to administration of a voluntary assisted dying substance, since July 2021, 15 patients who commenced the request and assessment process have withdrawn, including 4 patients in 2022–23. All patients who withdrew did so prior to an Administration Decision being made.

### **Administration Decision**

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.

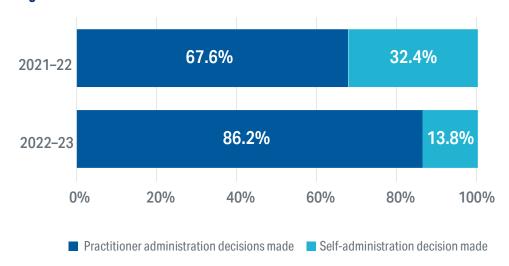
Self-administration of a voluntary assisted dying substance requires the patient to prepare and ingest the substance by swallowing or via a percutaneous endoscopic gastrostomy (PEG) or nasogastric (NG) tube. The patient must be able to complete these actions entirely by themselves. If a patient is unable 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 (IV) administration. More than one Administration Decision may be made if a patient changes their administration option (e.g., from self-administration to practitioner administration or vice versa).

Since 1 July 2021, 613 patients have made an Administration Decision, including 343 patients in 2022–23. This represents an increase of 24.7 per cent over the number of patients who made an Administration Decision in 2021–22 (n=275).

In 2022–23, 354 Administration Decisions were made<sup>11</sup>. Of these:

- 86.2 per cent (n=305) were practitioner administration decisions, an increase from 67.6 per cent (n=192) in 2021–22
- 13.8 per cent (n=49) were self-administration decisions, a decrease from 32.4 per cent (n=92) in 2021–22.

Figure 6: Administration Decisions made 2021–22 and 2022–23



The data shows a continued preference amongst patients for the voluntary assisted dying substance to be administered by an Administering Practitioner due to the patient's ability to administer the substance themselves (63.0%, n=192).

The prescription process commences 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.

<sup>11</sup> The data includes forms with a status of valid, void and revoked.

# Supply of the voluntary assisted dying substance

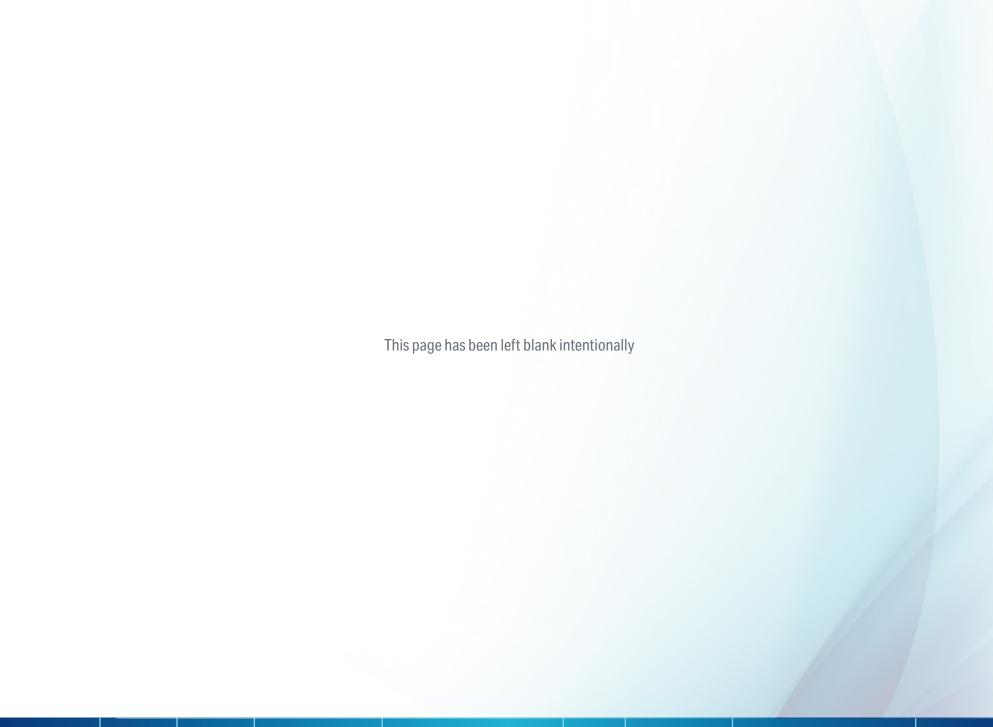
Supply of the voluntary assisted dying substance is a tightly controlled process initiated at the request of the patient. An Authorised Supplier at the Statewide Pharmacy Service can supply the voluntary assisted dying substance after receipt and authentication of a prescription from the Coordinating 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. 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). The Statewide Pharmacy Service travel to regional locations to ensure access to the voluntary assisted dying substance and to provide supporting information for patients and participating practitioners across Western Australia.

Since 1 July 2021, 504 patients, Contact Persons or Administering Practitioners have been supplied a voluntary assisted dying substance.

#### In 2022-23:

- 275 patients, Contact Persons or Administering Practitioners were supplied a voluntary assisted dying substance
- 8 patients had more than one supply, due to changing from a selfadministration to a practitioner administration or substance expiry
- 283 supplies occurred, a 19.4 per cent increase from 2021–22 (n=237).
   This included:
  - 83.7 per cent (n=237) supplies of the substance for practitioner administration, an increase from 67.9 per cent (n=161) in 2021–22
  - 16.3 per cent (n=46) supplies of the substance for self-administration, a decrease from 32.1 per cent (n=76) in 2021–22.



30 Contents Overview Health practitioners Voluntary assisted dying process Deaths Implementation Voluntary Assisted Dying Board Appendices

# Deaths

# Voluntary assisted dying deaths

Since 1 July 2021, 446 patients have died following administration of a voluntary assisted dying substance:

- 80.3 per cent of patients died after practitioner administration (n=358)
- 19.7 per cent of patients died after self-administration (n=88).

#### In 2022-23:

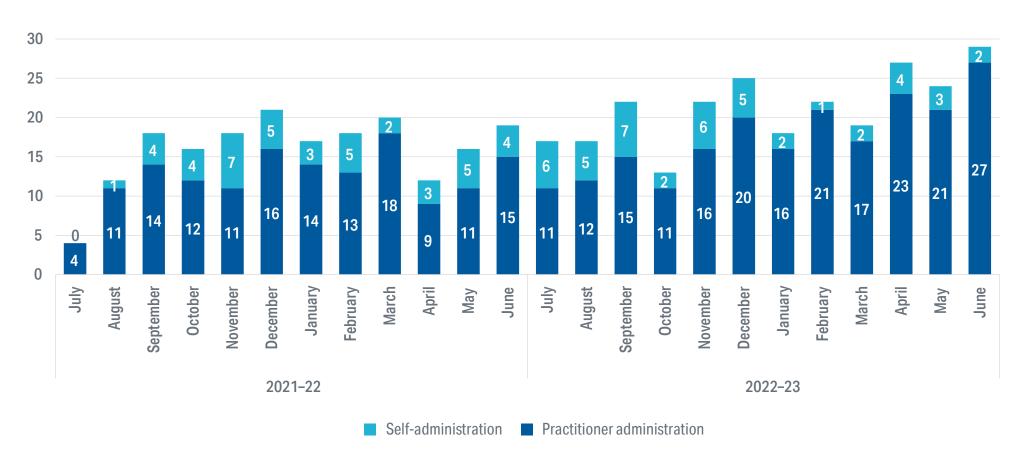
- there were 255 deaths recorded following administration of a voluntary assisted dying substance.
   This represents an increase of 33.5 per cent over the number of voluntary assisted dying deaths in 2021–22 (n=191)
- voluntary assisted dying deaths represented 1.4 per cent of the 17,900 total deaths in Western Australia<sup>12</sup>, an increase from 1.1 per cent in in 2021–22<sup>13</sup>
- the age range of patients when they died following administration of a voluntary assisted dying substance was between 30 and 99 years and the median age was 75 years. This compares similarly to 2021–22 (age range: 25–97, median age: 74).

The number of voluntary assisted dying deaths per month has increased over time. In 2022–23, the number of deaths per month ranged from 13 to 29. The average number of deaths per month in 2022–23 was 21, an increase from 16 deaths per month in 2021–22.

<sup>12</sup> Total deaths sourced from The Registry of Births, Deaths and Marriages, Department of Justice (2023).

<sup>13</sup> Voluntary Assisted Dying Board Annual Report 2021–22

Figure 7: Voluntary assisted dying deaths by month and administration type in 2021–22 and 2022–23

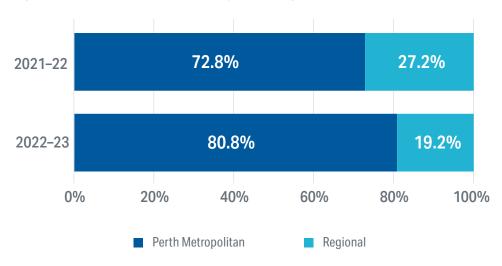


Implementation

#### **Location of residence**

In 2022–23, approximately 4 out of 5 patients who died following administration of a voluntary assisted dying substance resided in the Perth metropolitan region (80.8%, n=206). This has increased from 72.8 per cent in 2021–22 (n=139). Regional residents accounted for 19.2 per cent of deaths (n=49), a decrease from 27.2 per cent in 2021–22 (n=52).

Figure 8: Number of patient deaths by health region in 2021–22 and 2022–23



#### **Administration type**

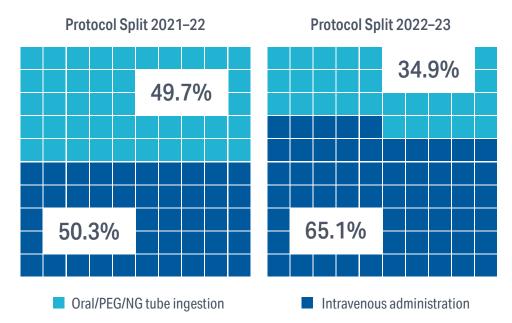
In 2022–23, there was an increased preference for practitioner administration of the voluntary assisted dying substance:

- 82.4 per cent of patients died after practitioner administration (n=210), an increase from 77.5 per cent in 2021–22 (n=148)
- 17.6 per cent of patients died after self-administration (n=45), a decrease from 22.5 per cent in 2021–22 (n=43).

In 2022–23, there was also an increased preference for intravenous administration of the voluntary assisted dying substance:

- 65.1 per cent of patients (n=166) died after intravenous administration of the voluntary assisted dying substance, an increase from 50.3 per cent in 2021–22 (n=96)
- 34.9 per cent of patients (n=89) died after Oral/PEG/NG tube administration of the voluntary assisted dying substance, a decrease from 49.7 per cent in 2021–22 (n=95).

Figure 9: Oral/PEG/NG tube ingestion vs intravenous administration in 2021–22 and 2022–23



#### **Process timeframes**

The Board monitors the length of time between the different stages of the voluntary assisted dying process to understand the operation of voluntary assisted dying, identify barriers to access and monitor voluntary assisted dying substance in the community.

#### First request to death

In 2022-23:

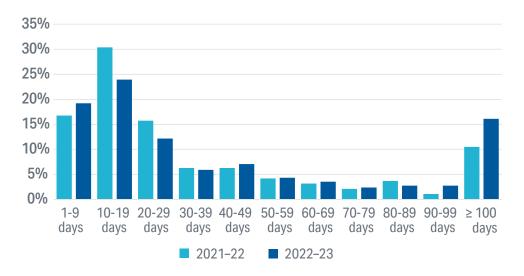
- the median number of days between First Request and death following administration of a voluntary assisted dying substance was 24 days, an increase from 21 days in 2021–22
- the median number of days for patients residing in the Perth metropolitan region and from regional areas were 26 and 22 days respectively
- the range of days between First Request and death was 2 days to 503 days.

The data demonstrates that the voluntary assisted dying process supports patients who make a First Request when they are close to death and those preparing for death.

Table 6: Day range between First Request and death in 2021–22 and 2022–23

	2021–22		2022–23	
	Perth metropolitan	Regional	Perth metropolitan	Regional
Shortest number of days	3	4	2	2
Longest number of days	213	224	503	282
Median number of days	20	22	26	22

Figure 10: Number of days between First Request and death in 2021–22 and 2022–23



#### Supply to death

In 2022-23:

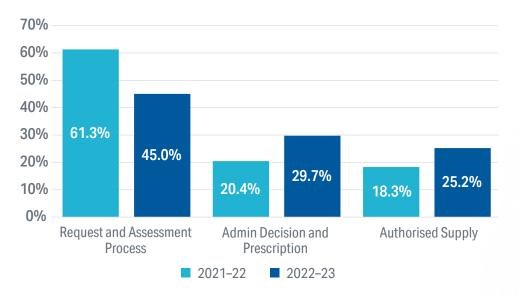
- the median number of days between supply and death following administration of a voluntary assisted dying substance was 1 day for practitioner administration and 4 days for self-administration
- the majority of patients died within 5 days of supply of the voluntary assisted dying substance (n=209, 81.9%)
- the longest number of days between supply and death for practitioner assisted Oral/PEG/NG tube administration was 230 days and self-administration was 473 days.

Since 1 July 2021, 8.7 per cent of patients who were supplied a voluntary assisted dying substance died prior to substance administration (n=45). On each occasion where this occurred the Board has received notification of substance disposal.

#### Death prior to administration of a voluntary assisted dying substance

Since July 2021, 204 patients who commenced the request and assessment process died prior to administration of a voluntary assisted dying substance including 111 patients in 2022–23. More than half (n=61, 55.0%) died after the completion of the Request and Assessment process.

Figure 11: Voluntary assisted dying process stage of patients who died prior to administration of a voluntary assisted dying substance



#### **Practitioner administration**

When a patient dies via practitioner administration, the Administering Practitioner is required to record the circumstances in which the administration took place, including the time that elapsed between administration of the substance and death, the location of administration, and complications relating to the administration of the substance<sup>14</sup>.

#### Time to death after practitioner administration

In 2022–23, after practitioner intravenous administration:

- the median time to death was 5 minutes, a decrease from 8 minutes in 2021–22
- 93.4 per cent of patients died within 15 minutes
- time elapsed between substance administration and death ranged from 1 minute to 30 minutes.

In 2022–23, after practitioner assisted oral ingestion or assisted ingestion via PEG or NG tube:

- the median time to death was 19 minutes, an increase from 15 minutes in 2021–22
- 88.6 per cent of patients died within 60 minutes
- time elapsed between substance administration and death ranged from 7 minutes to 6 hours 29 minutes.

Table 7: Length of time to death of patient via intravenous administration in 2021 to 2023

P5 Length of time to death	2021–22	2022-23	Total	% of total
≤ 15 minutes	90	155	245	93.5%
≥ 16 minutes	6	11	17	6.5%
Total	96	166	262	100.0%

Table 8: Length of time to death of patient via assisted oral ingestion, assisted ingestion via PEG or NG tube in 2021 to 2023

P3/P4 Length of time to death	2021–22	2022-23	Total	% of total
≤ 29 minutes	42	30	72	75.0%
30 to 60 minutes	6	9	15	15.6%
≥ 61 minutes	4	5	9	9.4%
Total	52	44	96	100.0%

<sup>14</sup> No data on length of time to death, administration location or complications is collected by the Voluntary Assisted Dying Board regarding deaths occurring via self-administration of the voluntary assisted dying substance.

#### **Administration location**

As in 2021–22, the primary location for practitioner administration of the voluntary assisted dying substance in 2022–23 was the patients' home (n=96, 45.7%). In 2022–23, there was an increase in the percentage of administrations occurring in a public hospital ward, from 19.6 per cent in 2021–22 to 33.3 per cent in 2022–23. There was a decrease in the percentage of administrations occurring in the patients' home, residential aged care and hospice or palliative care unit.

Figure 12: Number of patient deaths by practitioner administration location in 2021 to 2023

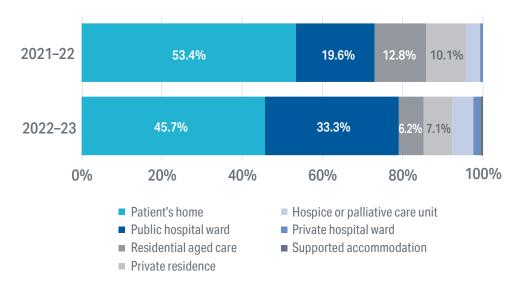


Table 9: Number of patient deaths by practitioner administration location in 2021 to 2023

Practitioner administration location	2021–22	2022–23	Total	% of total
Patients' home	79	96	175	48.9%
Public hospital ward	29	70	99	27.7%
Residential aged care	19	13	32	8.9%
Hospice or palliative care unit	15	15	30	8.4%
Private residence	5	11	16	4.5%
Private hospital ward	1	4	5	1.4%
Supported accommodation	0	1	1	0.3%
Total	148	210	358	100.0%

Contents

#### **Complications**

At the time of administration, practitioners are required to notify the Board of any complications that occur during the administration. In 2022–23, 94.3 per cent of deaths following practitioner administration (n=198) were reported without complication, which has decreased from 97.3 per cent in 2021–22 (n=144). There were 13 complications reported in 2022–23 (5.7% of deaths), with one patient episode recording more than one complication.

Intravenous line complications were recorded as the most common complication (n=7), followed by other (n=5) and worsening of pain or discomfort (n=1). Complications reported as other included coughing, burning of the throat following assisted oral ingestion, transient agitation and pain following injection following intravenous administration. All patients with reported complications died after administration of the voluntary assisted dying substance. The Board completed case reviews of all reported complications.

38 Contents Overview Health practitioners Voluntary assisted dying process Deaths Implementation Voluntary Assisted Dying Board Appendices

## 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* (the Act). 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 Act.

In 2022–23, 4,407 forms<sup>15,16</sup> were received by the Board, representing a 20.6 per cent increase in activity from 2021–22. Form submission increased steadily month to month, peaking in May 2023. An average of 367 forms were received each month, an increase from 304 forms per month in 2021–22.

Significant increases were observed in the number of submitted Practitioner Administration Forms (increase of 43.5%), Authorised Disposal Forms (increase of 69.2%) and Administering Practitioner Disposal Forms (increase of 64.4%). It is of note, that while other stages of the request and assessment process experienced an increase of between 20 to 23 per cent, the number of First Request Forms increased by 3.7 per cent.

It is a requirement of the Act that approved forms be given to the Board within 2 business days of a specified event taking place. This aims to ensure that key tasks in the voluntary assisted dying process are completed and documented in a timely manner and that the process can continue to progress for a patient seeking access to voluntary assisted dying. In 2022–23, 96.5 per cent of forms were submitted to the board within 2 business days. Where failure to give a form to the Board within the required timeframe is an offence under the Act, a referral has been made to the Chief Executive Officer of the Department of Health.

<sup>15</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>16</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:

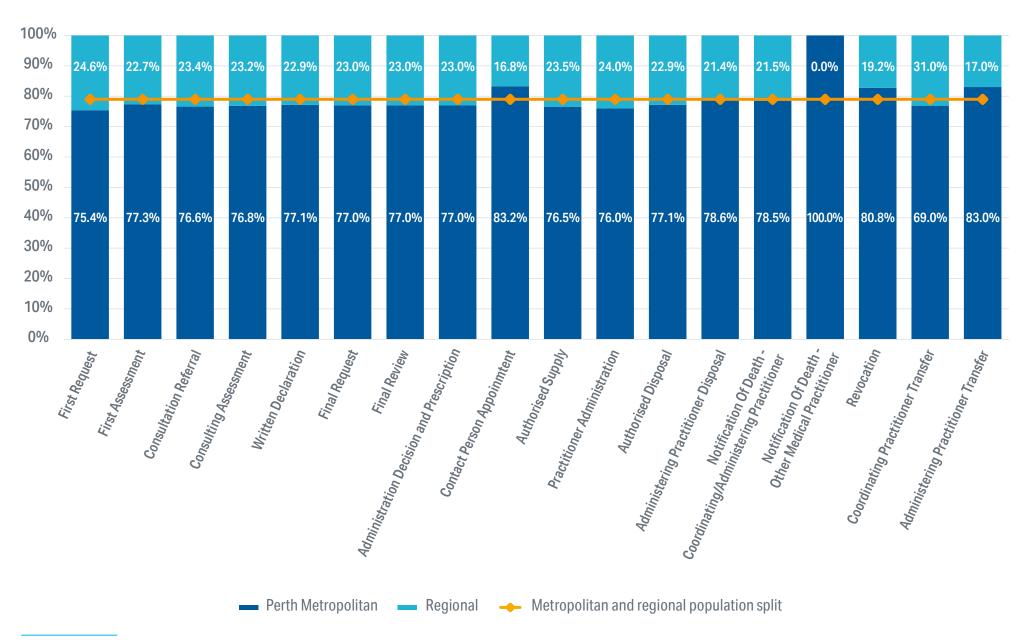
A form is assigned a status of 'void' when a subsequent Consulting Assessment Form is submitted, or a form has been superseded by another valid submission.

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 10: Number of forms with a status of valid, void and revoked submitted in 2021–22 and 2022–23

			All time		
Form title	2021–22	2022–23	Total	Perth metropolitan	Regional
First Request	726	753	1,479	1,115	364
First Assessment	383	472	855	661	194
Consultation Referral	337	406	743	569	174
Consulting Assessment	324	397	721	554	167
Written Declaration	293	363	656	506	150
Final Request	284	347	631	486	145
Final Review	284	347	631	486	145
Administration Decision and Prescription	284	354	638	491	147
Contact Person Appointment	93	50	143	119	24
Authorised Supply	237	283	520	398	122
Practitioner Administration	147	211	358	272	86
Authorised Disposal	13	22	35	27	8
Administering Practitioner Disposal	90	148	238	187	51
Notification Of Death - Coordinating/Administering Practitioner	114	175	289	227	62
Notification Of Death – Other Medical Practitioner	2	0	2	2	0
Revocation	9	17	26	21	5
Coordinating Practitioner Transfer	17	25	42	29	13
Administering Practitioner Transfer	16	37	53	44	9
Total	3,653	4,407	8,060	6,194	1,866

Figure 13: Number of forms with a status of valid, void and revoked by health region submitted in 2021 to 2023<sup>17</sup>



<sup>17</sup> Metropolitan and regional population data sourced from Epidemiology Directorate, Public & Aboriginal Health Division, Department of Health (2023).

# 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 support the implementation of voluntary assisted dying through:

- management of the practitioner verification process to access the online WA VAD Approved Training and Prescription and Administration Information
- provision of information resources and educational material for patients, patient families and carers, and practitioners through the Department of Health website and reviewing resources to ensure they are fit for purpose
- working closely with Health Service Providers to support the operation of voluntary assisted dying within the WA health system
- contract management for the statewide services
- promotion of the WA VAD Approved Training including supporting practitioner training days where practitioners can complete the online modules alongside other participants and meet representatives from the statewide services and Community of Practice.

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

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

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. The SWNCS is pivotal to the success of voluntary assisted dying in Western Australia.

Since the inception of the SWCNS, a total of 21,707 interactions have been recorded including contact from 1,146 patients, 41 others, 176 health care workers and 57 training requests<sup>18</sup>.

During 2022–23, the SWCNS provided:

- 11,602 interactions with patients, families and carers, health care workers and practitioners, including 700 new requests for support
- initial conversations with an average of 150 new patients per quarter
- support for an average caseload of 266 patients per quarter (combined new referrals and ongoing follow ups).

The SWCNS provided a range of support services during 2022–23 with care coordination (n=2,887, 37.3%) being the most common type of interaction, followed by ongoing care (n=2,493, 32.2%). Close to 10 per cent of interactions (n=802) related to assistance in finding a participating practitioner. This remains consistent with the support services provided in 2021–22.

<sup>18</sup> Data supplied by the Statewide Care Navigator Service.

Table 11: Statewide Care Navigator Service interactions in 2021 to 2023<sup>19</sup>

Primary interaction type	2021–22	2022–23	Total	% of total
Care coordination	1,794	2,887	4,681	34.6%
Ongoing care	2,036	2,493	4,529	33.5%
Enquiry/information request	1,058	1,156	2,214	16.4%
Seeking practitioner	634	802	1,436	10.6%
Other	230	68	298	2.2%
Bereavement support	2	206	208	1.5%
Administration support	1	104	105	0.8%
Support request - individual	7	10	17	0.1%
Support request - family/carer	3	13	16	0.1%
Regional Access Support Scheme	8	3	11	0.1%
Total	5,773	7,742	13,515	100.0%

The Board acknowledges the continued success of the SWCNS in providing a responsive, person-centred care navigation service with equitable access across metropolitan and regional areas in 2022–23 with achievements including:

- receipt of additional funding to increase staffing to address a continued greater than expected demand
- refinement of processes and team structures to meet demand

- · review and refinement of data capture, analysis and reporting
- identification of and planning for grief and bereavement resources, supports and education
- improved understanding of the burden of workload on the relatively small cohort of participating practitioners and the development of strategies and supports to attract and retain the practitioner workforce
- participation in bi-monthly online meetings of the National Care Navigator Community of Practice to share learnings, information, education and support.

The Board understands the challenges raised by the SWCNS to ensure the service can continue to support Western Australians seeking information about or access to voluntary assisted dying including:

- sustainability of the existing care navigator workforce and ability to address workload, backfill of staff leave, career development, and staff recruitment and retention
- increase in caseload and complexity of end-of-life care case management in the context of voluntary assisted dying of patients, including those within faith-based facilities and those with psychosocially complex contexts. Many cases have multiple interactions, both of care coordination and ongoing care, before arriving at a First Assessment appointment with a voluntary assisted dying practitioner
- balance of demand, capacity and burnout across the practitioner workforce when engaging practitioners for referrals. The burden of the workload and concerns regarding remuneration impacts on the outcomes of attempting to engage practitioners
- a number of practitioners expressing the need to suspend and/or scale back their availability to consider referrals from the SWCNS through the reporting year.

43

<sup>19</sup> Bereavement support, administration support, support request - family/carer and support request - individual was initially captured in 'Other' and have been reported separately in 2022-23.

#### **Regional Access Support Scheme**

The Regional Access Support Scheme (RASS) was developed under the Access Standard required by the Voluntary Assisted Dying Act 2019 and is managed by the SWCNS. The RASS provides financial support to ensure that regional residents are not disadvantaged in their ability to access voluntary assisted dying including travel for practitioners, patients, support persons and interpreters involved in the voluntary assisted dying process. The RASS was reviewed after the first year to ensure it continues to be fit for purpose, utilises resources appropriately and is consistent with the intentions of the Access Standard. In 2022-23, amendments to the scope of the RASS eligibility criteria were made including utilisation of funds for:

- additional travel and accommodation purposes
- completion of the WA VAD Approved Training by a medical practitioner or nurse practitioner who cares for regional patients
- supply of a prepaid data device and associated postage costs, where videoconferencing cannot otherwise be made available to a regional resident
- additional activities to support regional access and sustainability of voluntary assisted dying, as approved by the Department of Health.

In 2022–23, there were a total of 145 requests that met the defined RASS criteria in support of 78 patients, an increase from 108 requests in support of 50 patients in 2021–2218. Almost all requests (n=138, 95.2%) were made for travel of a practitioner to a patient for face-to-face care, which is consistent with 2021–22 (n=117, 92.1%)<sup>20</sup>.

RASS requests were received from all regions. In 2022–23, the amended scope of the RASS allowed funding to be used to better support patients living in outer metropolitan suburbs where challenges had been experienced in sourcing and engaging practitioners due to the time and travel required. This change has been acknowledged by the SWCNS as a contributing factor to the increase in requests and equity of access for patients in outer metropolitan areas. The lack of practitioners who have completed the WA VAD Approved Training in the Wheatbelt continues to create demand for RASS support. In 2022–23, requests were most likely to be received for patients residing in the Perth metropolitan (n=52, 35.9%) and Peel (n=31, 21.4%) regions.

**Table 12: Regional Access Support Scheme Requests by health region in** 2021-22

Region	2021–22	2022-23	Total	% of total
Goldfields	13	2	15	5.9%
Kimberley	2	4	6	2.4%
Midwest	0	4	4	1.6%
Great Southern	20	19	39	15.4%
Peel	29	31	60	23.7%
Perth metropolitan	2	52	54	21.3%
Pilbara	2	3	5	2.0%
South West	22	20	42	16.6%
Wheatbelt	18	10	28	11.1%
Total	108	145	253	100.0%

Deaths

<sup>20</sup> One RASS request may involve several types of support, such as travel and accommodation, such that overall RASS request numbers may not be equal to the total number of RASS requests.

#### **Statewide Pharmacy Service**

The Statewide Pharmacy Service (SWPS) 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 role of SWPS pharmacists as Authorised Suppliers ensures the substances are provided directly to the patient or their representative, or to the Administering Practitioner.

#### During 2022–23<sup>21</sup>:

- the SWPS experienced an increase in voluntary assisted dying substance supplies, supplying the prescribed voluntary assisted dying substance on 283 occasions, an increase from 237 in 2021–22
- the number of visits per month for supply ranged from 15 to 31.

In 2022–23, the SWPS travelled within the Perth Metropolitan region (n=244, 86.2%), South West (n=17, 6.0%), Great Southern (n=14, 4.9%), Midwest (n=7, 2.5%) and Pilbara (n=1, 0.4%) to supply the voluntary assisted dying substance to patients, Contact Persons or Administering Practitioners. No travel occurred to the Goldfields, Kimberley or Wheatbelt. Whilst in 2021–22 SWPS travelled to every region, the distribution of travel between metropolitan and regional remains consistent (Perth metropolitan n=203, 85.7%; regional n=34, 14.3%). This change is attributed to the increasing preference for practitioner administration and metropolitan based practitioners supporting patients residing in regional areas<sup>22</sup>.

All supplies to the Perth metropolitan area (n=244) occurred within 2 business days and 97.5 per cent of supplies to a regional area (n=38) within 5 business days of the patient or Administering Practitioner's requested timeframe. One supply event occurred outside of the requested timeframe due to a delay in appointment of a Contact Person, and once the Contact Person was appointed, supply occurred within 2 business days. This is similar to 2021–22.

The Board acknowledges the maintenance of the high quality and safety standards and achievements of the SWPS in 2022–23 including:

- receipt of additional funding to increase staffing in the service and to ensure continued supply of the voluntary assisted dying substance
- doubling the number of credentialled pharmacists working with the service
- streamlining the approval process for SWPS staff travel to support timely access to the voluntary assisted dying substance
- continued active participation in practitioner training and education
- implementing regular monitoring of voluntary assisted dying substance in the community
- supporting practitioners by acting as a witness to administration
- updating disposal guidance to better support Authorised Disposer's in the community.

The Board understands the challenges raised by the SWPS surrounding the inability to discuss voluntary assisted dying substances over a carriage service due to the contravention of the *Commonwealth Criminal Code Act 1995* and the added complexity this creates for the SWPS in delivering its functions by restricting:

- telehealth or telephone support and counselling to patients or practitioners on specifics of voluntary assisted dying substances
- digital supply of prescriptions from remote and regional practitioners to enable more timely dispensing and supply
- telehealth counselling in health service facilities that object to the SWPS being on-site where the patient is not able to collect the substance in person
- online collaboration with voluntary assisted dying pharmacy services in other jurisdictions to focus on service improvements

**Appendices** 

45

 digital education opportunities or platforms for the prescribing and administration of voluntary assisted dying substances.

Overview

Contents

<sup>21</sup> Data supplied by the Statewide Pharmacy Service.

<sup>22</sup> Region where supply of the voluntary assisted dying substance occurs may not align with the patient's home address. e.g., supply of a voluntary assisted dying substance for regional residents may occur in the Perth metropolitan region.

#### **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 as well as staff from the SWCNS and the SWPS. In 2022–23, membership of the Community of Practice continued to grow, now comprising 90 members including 68 practitioners who have completed the WA VAD Approved Training. The Community of Practice meets monthly so that practitioners and others involved in the voluntary assisted dying process in Western Australia can share learnings in a confidential and collegiate space. Meetings alternate between in-person and hybrid online formats to encourage the engagement of practitioners based in regional Western Australia. Support for the Community of Practice is provided by the SWCNS.

In 2022–23, the Community of Practice transitioned to utilising a more inclusive, user-friendly and secure online platform for communications, sharing meeting outcomes and resources. The platform is jointly managed by an identified Community of Practice leadership team with representatives from SWCNS, SWPS, two hospital-based practitioners and a General Practitioner. The leadership group work actively to establish mentoring connections for new/incoming practitioners and update the platform with resources and information relevant to the group.

Participating practitioners wishing to join the Community of Practice can contact <u>VADcarenavigator@health.wa.gov.au</u>

46 Contents Overview Health practitioners Voluntary assisted dying process Deaths Implementation Voluntary Assisted Dying Board Appendices

## Voluntary **Assisted Dying** Board

## Voluntary Assisted Dying Board

On 1 July 2021, voluntary assisted dying became a choice for eligible Western Australians under the Voluntary Assisted Dying Act 2019 (the Act). The development of the Act was preceded by the Parliamentary Joint Select Committee on End-of-Life Choices report My Life, My Choice and the Ministerial Expert Panel on Voluntary Assisted Dying Final Report.

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

#### **Functions**

The Act sets out the following functions for the 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 and meetings

The 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 (Chairperson)**

Dr Blackwell is a General Practitioner and former Australian Medical Association Western Australia Branch President. Dr Blackwell has expertise in palliative and aged care and was the Chairperson of the Implementation Leadership Team on voluntary assisted dying.



#### 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 Office of Multicultural Interests and Office of Women's Policy. Ms Osman is a board member of the Child and Adolescent Health Service, University of Western Australia International Public Policy Institute, and the Gnaala Karla Booja Aboriginal Corporation. Ms Osman was a member of the Ministerial Expert Panel on voluntary assisted dying.



#### **Hon Colin Holt (Deputy Chairperson)**

Mr Holt was a Member of the Legislative Council of Western Australia, representing the South West Region, from 2009 to 2021. Mr Holt is a board member of the WA Country Health Service and Racing and Wagering Western Australia. Mr Holt was the Deputy Chairperson of the Joint Select Committee on End-of-Life Choices.



#### Ms Linda Savage

Ms Savage is a lawyer and former Director of the Social Security Appeals Tribunal, legal member of the Administrative Appeals Tribunal and Member of the Legislative Council representing the East Metropolitan Region. Ms Savage is a past board member of Dying with Dignity Western Australia. Ms Savage is a board member of the University of Western Australia International Public Policy Institute, the National Drug Research Institute, Children and the Media Australia, the Gaming Community Trust and Upswell Publishing. In 2018, she was appointed an Ambassador for Children and Young People in Western Australia.



#### **Dr Robert Edis**

Dr Edis is a Consultant Neurologist with a with a long-time interest in progressive neurological diseases including special experience in multidisciplinary team motor neurone disease care. Dr Edis strongly supports voluntary assisted dying to be available as an end-of-life choice for eligible people with these diseases.

48

The Board met monthly throughout 2022–23. All meetings were held in accordance with the requirements of the Act. Additional workshops were held for risk management, strategic planning, and preparation of the 2021-22 Annual Report.

Table 13: Board member term and meeting attendance 2022–23

Board member	Term	Meetings attended
Dr Scott Blackwell	1 July 2021 to 30 June 2024	11 of 12
Colin Holt	1 July 2021 to 30 June 2023 (Reappointed for a further 2 years, commencing 1 July 2023)	11 of 12
Dr Robert Edis	1 July 2021 to 30 June 2023 (Reappointed for a further 2 years commencing 1 July 2023)	11 of 12
Maria Osman	1 July 2021 to 30 June 2024	11 of 12
Linda Savage	1 July 2021 to 30 June 2023 (Reappointed for a further 3 years commencing 1 July 2023)	11 of 12

#### **Board Performance**

In 2022–23, the Board developed a performance review policy and evaluated the performance of the Board. The review included individual self-assessment and evaluation of performance, and one-on-one performance review meetings with the Board Chair. Board members were satisfied with the performance of the Board and identified stakeholder engagement and strategic planning as areas of additional focus for the coming year.

#### **Board Support**

The Voluntary Assisted Dying Board Secretariat Unit (Secretariat Unit) supports the day-to-day operations of the Board, including the management of the Voluntary Assisted Dying Information Management System (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 Board to deliver its functions and legislated obligations.

#### **Directions and disclosures**

In 2022–23, no directions were given by the Minister pursuant to section 123(1) or 152(2) of the Act. No disclosures of material or personal interest made by Board members under section 140(1) related 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. For 2022–23, there were no issues in relation to the Voluntary Assisted Dying Board Code of Conduct.

## Monitoring

The Board is responsible for monitoring the operation of the Act. The Voluntary Assisted Dying Board Monitoring Function Policy details the principles and processes that guide the Board's monitoring functions including real time and routine monitoring.

The 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**

In accordance with the Voluntary Assisted Dying Board Monitoring Function Policy, the Board undertakes monthly case reviews of a minimum of 20 per cent of closed individual patient episodes to monitor compliance with the Act. Patient episodes are identified for case review from a range of criteria including actual or suspected non-compliance, long standing patients and complications reported after practitioner administration. A patient episode may be closed at various points during the voluntary assisted dying process, including if the patient is assessed as not eligible, has withdrawn from the process or has died.

The Board completed 88 case reviews during 2022–23. Key actions arising from the case review process included:

- updates to the Voluntary Assisted Dying Board Monitoring Function Policy to amend the case review template, type and frequency of monitoring reports and process for escalation of episodes to the Board
- referrals to the Chief Executive Officer of the Department of Health regarding timeliness of disposal of a voluntary assisted dying substance
- engaging with Health Service Provider Voluntary Assisted Dying Coordinators to understand the implementation of voluntary assisted dying within the WA health system

- · recommendations for practitioner education including:
  - Statewide Care Navigator Service referral pathway after a First Request is refused
  - patient/family counselling on length of time to death following oral administration of a voluntary assisted dying substance
  - requirement for timely disposal of voluntary assisted dying substances by Authorised Disposer's and reporting disposals to the Board
  - voluntary assisted dying as an end-of-life choice for Aboriginal people.

#### **Referrals**

Section 118(c) of the Act 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 2022–23, the Board made referrals to the Chief Executive Officer of the Department of Health relating to the timeliness of an authorised disposal of a voluntary assisted dying substance (n=3), the timeliness of forms submitted to the Board (n=164) and informing the person making a First Request and the Board of the outcome of a First Request (n=1).

50 Contents Overview Health practitioners Voluntary assisted dying process Deaths Implementation Voluntary Assisted Dying Board Appendices

### Education, data and research

#### Education

In 2022–23, the Board published 4 editions of the Quality Practice Series. The Quality Practice Series is intended to be a series of tips, reminders and practice points for participating practitioners that focus on different areas of the voluntary assisted dying process. Topics included:

- requirements for form submission including timeliness, accuracy and notifying the Board following patient death
- sequencing of the Final Review and Administration Decision and Prescription
- determining prognosis and referral for determination
- the role of the Contact Person
- submission of personal reflections
- supporting patients in planning for death
- upgrades to VAD-IMS
- completion of practitioner profiles on VAD-IMS.

In 2022–23, the Board Chair engaged with the Community of Practice to share information and receive feedback from those participating in the voluntary assisted dying process. Topics discussed with the Community of Practice included:

- form submission timeliness
- barriers to access to voluntary assisted dying for patients in private facilities
- length of time to death following oral administration of a voluntary assisted dying substance
- practitioner fatique and remuneration
- mentoring and induction of new practitioners
- longstanding patients and voluntary assisted dying substance in the community.

#### **Data and research**

One of the functions of the Board is to conduct analysis of, and research in relation to, information received throughout the voluntary assisted dying process. In 2022–23, the Board developed and endorsed a research policy that sets out the Board's intended approach to research, aligned to strategic objectives. The policy includes research focus areas to support the Board's understanding of:

- awareness and understanding of voluntary assisted dying
- barriers to access and patient experience
- practitioner involvement in voluntary assisted dying and current workforce issues.

The Board has provided in principle support for participation in inter-jurisdictional research, led by Queensland University of Technology, into the operation of voluntary assisted dying in Australia.

In 2022–23, the Board participated in the National Minimum Dataset Working Group with other Australian jurisdictions to work towards an agreed set of reporting measures for voluntary assisted dying. Proposed national minimum dataset reportable items for 2022–23 are included at Appendix 3.

The Board also commenced development of governance mechanisms to respond to requests for information in compliance with the provisions of the Act. This included endorsing an information disclosure model, information request and release process and draft information governance policy.

In accordance with the provisions of section 151 of the Act, the Board disclosed information in response to 6 requests for information during 2022–23. Aggregated activity data was released to support health service planning, quality improvement and education.

## Stakeholder engagement

In 2022–23, the Board developed and endorsed a stakeholder engagement policy to outline a planned approach to engagement in support of the successful performance of the Board's functions under the Act. A strong culture of engagement and collaboration supports the Board to:

- develop sustainable partnerships
- build trust through open and transparent communication
- · reduce risk by identifying and managing emerging issues
- provide stakeholders the opportunity to articulate concerns at an early stage.

The Board also met with the Minister for Health and Chief Executive Officer of the Department of Health to discuss the operation and recommendations for improvement of the Act, including themes raised in recommendations made by the Board.

Board meetings include a regular program of guest speakers throughout the year to discuss the operation of voluntary assisted dying and specific issues of interest of the Board. In 2022–23, guest speakers included the End-of-Life Care Clinical Lead, Statewide Care Navigator Service, Statewide Pharmacy Service, Community of Practice Leadership Group, Chief Executive Officer and the Chief Medical Officer of the Department of Health. The Board also engaged with the Australian Centre for Health Law Research at Queensland University of Technology and heard from subject matter experts on grief and bereavement, and cybersecurity.

In May 2023 the Board conducted a regional meeting and engagement activities in Albany. The visit to the Great Southern enabled the Board to monitor the operation of the Act with a focus on the successful integration of voluntary assisted dying and palliative care, and participation in voluntary assisted dying by regional health practitioners. The Board met with voluntary assisted dying practitioners, palliative care practitioners, community members, family members and staff from the Albany Community Hospice.

Other stakeholder engagement activities undertaken by Board Members during 2022–23 included interjurisdictional engagement, attending a meeting of the Bunbury Death Café, participation in a voluntary assisted dying forum hosted by Medical Defence Australia, attending the Community of Practice and participation in the Voluntary Assisted Dying Memorial Service following the first year of operation.

52 Contents Overview Health practitioners Voluntary assisted dying process Deaths Implementation Voluntary Assisted Dying Board Appendices

### Recommendations

Following the first year of operation of the Voluntary Assisted Dying Act 2019 (the Act) the Board identified key areas for improvement to voluntary assisted dying and made recommendations on:

- the need for more practitioners to participate and complete the WA VAD **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
- adequate and ongoing funding to support the operation of the Act and access to voluntary assisted dying for eligible Western Australians including regional residents
- identification of areas for review of the Act.

The Board acknowledges support of the Western Australian Government in its response to the recommendations raised in the 2021–22 Annual Report. Throughout 2022–23, the Board has continued its advocacy and monitored activity in areas identified in recommendations, noting that ongoing efforts are required to address the remuneration of participating practitioners and the impacts of the Commonwealth Criminal Code Act 1995. The Board has made further recommendations in this regard to ensure the effective operation of voluntary assisted dying in Western Australia, including access for regional residents. These critical issues should be addressed as a matter of priority.

At the conclusion of the second year, the Board provide the following additional observations and recommendations for the improvement of voluntary assisted dying.

#### Improving access to voluntary assisted dying in health service facilities

In 2022–23, concerns were raised with the Board from patients, their families, participating practitioners and statewide service providers, regarding barriers to access to voluntary assisted dying for patients residing in health service facilities, such as private hospitals, including those providing public health services as contracted health entities.

#### Concerns raised included:

- the lack of published information about institutions with an objection to voluntary assisted dying
- multiple same-day transfers of patients with complex medical needs to off-site locations due to the inability of patients to make requests or be assessed on-site or via videoconference
- lack of compassion and support for patients and families
- barriers to accommodating patient wishes for chosen location for administration of a voluntary assisted dying substance.

The Act does not currently contain provisions to support access to voluntary assisted dying for patients who are permanent or non-permanent residents of health service facilities. The Act does not require health service facilities to publicly disclose when they do not provide access to voluntary assisted dying.

To ensure the principles of the Act are upheld, specific provisions should be included in the Act to ensure health service facilities, including those with an institutional objection, do not impede access to voluntary assisted dying.

#### **Recommendation 1:** The Act is amended to include:

- protections for access to voluntary assisted dying for patients and residents of health service facilities
- the requirement for public information to be available on whether a health service facility provides access to voluntary assisted dying.

**Recommendation 2:** Improve access to public information on voluntary assisted dying availability in health service facilities, particularly where voluntary assisted dying is not available as an end-of-life choice.

#### **Exemption to citizenship and residency requirements**

The Act requires that a person accessing voluntary assisted dying is an Australian citizen or permanent resident who has, at the time of making a First Request, been ordinarily resident in Western Australia for a period of at least 12 months.

The Board is aware that these provisions may restrict access to voluntary assisted dying for patients who:

- have resided in Australia for a significant period of time but are not Australian citizens or permanent residents
- have a substantial connection to Western Australia but who have not been ordinarily resident for 12 months prior to making a First Request
- have been assessed as eligible in another Australian State and want to relocate to Western Australia to be closer to family and social supports during their end of life.

#### **Recommendation 3:** The Act is amended to:

- expand access to voluntary assisted dying for long-term Australian residents who are not an Australian citizen or permanent resident
- provide an exemption pathway to the ordinary residency requirements for people who have a substantial connection to Western Australia or have been found eligible in another Australian jurisdiction.

#### **Nurse practitioner participation**

Nurse practitioners can participate in the voluntary assisted dying process as an Administering Practitioner. In 2022–23, 7 nurse practitioners completed the WA VAD Approved Training, with 1 nurse practitioner participating as an Administering Practitioner.

The Board acknowledges the barriers presented to nurse practitioners to take on the role of Administering Practitioner, where there has not been opportunity to develop relationships with patients and families prior to administration, and recognises the need for nurse practitioners to be utilised more effectively as part of the voluntary assisted dying process.

A recent study by Queensland University of Technology on the operation of the Act in Western Australia highlighted the need for consideration of expanded roles for nurse practitioners to be involved beyond the role of Administering Practitioner<sup>23</sup>.

#### **Recommendation 4:** Strategies are developed to:

- increase nurse practitioner participation in voluntary assisted dying
- effectively utilise and provide mentorship to participating nurse practitioners in the voluntary assisted dying process.

**Recommendation 5:** The review of the Act should include consideration of nurse practitioners participating as Coordinating or Consulting Practitioners in the voluntary assisted dying process.

<sup>43</sup> Haining, C.M., Willmott, L., & White, B.P. (2023). Comparing voluntary assisted dying laws in Victoria and Western Australia: Western Australian stakeholders' perspectives. Journal of Law and Medicine, 30 (in press).

#### **Implementation of the First Request process**

The Board has observed that patients, families, and health practitioners may be unaware of the requirements of the Act in relation to First Requests, particularly the need for the patient to make a new First Request if an initial First Request has been refused. Submission of a First Request Form to the Board does not trigger a referral to the Statewide Care Navigator Service. In 2022–23 the Board improved information provided on receipt of refused First Request Forms to advise medical practitioners of the care navigator referral pathways. In 2022–23, 107 patients who made a First Request that was refused did not go on to make a further First Request during the reporting period.

Public information, including the Approved Information for a person making a First Request for voluntary assisted dying booklet (Approved Information), should provide appropriate guidance to patients on how to locate a practitioner who will accept a First Request. Implementation of the First Request process should be reviewed to ensure that it is meeting the objectives of the Act and is not creating barriers to access to voluntary assisted dying.

**Recommendation 6:** Improve public information, including the Approved Information, to increase awareness of how to locate a practitioner who is willing and eligible to accept a First Request.

**Recommendation 7:** Implement strategies to increase health practitioner awareness of the requirements of the Act and their obligations when a First Request is received from a patient.

**Recommendation 8:** The review of the Act considers the implementation and effectiveness of the First Request process.

#### Requirement for prescriptions to be given directly to an Authorised Supplier

The Act requires the Coordinating Practitioner give a prescription for a voluntary assisted dying substance directly to the Authorised Supplier. Prescriptions are required to be provided in hard copy as the *Commonwealth Criminal Code Act 1995* limits the use of a carriage service to access and transmit suicide-related material. These requirements are operationalised in the Prescription and Administration Information for prescriptions to be provided in person, via registered post or courier.

The requirement for a hard copy prescription to be given to an Authorised Supplier can act as a barrier to accessing voluntary assisted dying due to the geographical expanse of Western Australia, standard delivery times of postal and courier services in comparison to the speed at which the patient progresses through the voluntary assisted dying process.

To ensure patients have timely and equitable access to prescribed voluntary assisted dying substances, section 70(6) of the Act should be amended to account for scenarios where there are barriers for the prescription to be provided directly by the Coordinating Practitioner to the Authorised Supplier.

**Recommendation 9:** Amendments to the *Commonwealth Criminal Code Act* 1995 to support electronic prescribing of the voluntary assisted dying substance.

**Recommendation 10:** The review of the Act considers allowing persons other than the Coordinating Practitioner to deliver prescriptions for a voluntary assisted dying substance to an Authorised Supplier, until such time as the *Commonwealth Criminal Code Act 1995* is amended to allow electronic prescriptions.

#### Information sharing with care navigators

The Act includes provisions on recording, use or disclosure of information to protect patient privacy. The Act permits the sharing of information for the purpose of performing a function under the Act, however there is no provision for sharing or disclosing personal information beyond the provisions of the Act. This includes the Board sharing information with the Statewide Care Navigator Service and Health Service Provider Voluntary Assisted Dying Coordinators who support patients through the voluntary assisted dying process. These service providers have a pivotal role in the overall successful operation of voluntary assisted dying, however, do not have a function under the Act. As a result, this impacts on the ability of these services to provide their functions including care navigation and information provision, the Board's monitoring function and the overall safety and quality of voluntary assisted dying.

**Recommendation 11:** The Act be amended to designate a function for service providers who offer care navigation services for patients accessing voluntary assisted dying.

#### **Establishment of a cannulation service**

In the second year of operation, there has been an increasing preference for intravenous practitioner administration of the voluntary assisted dying substance (79.0% of all practitioner administration deaths and 65.1% of total voluntary assisted dying deaths). In 2022–23, intravenous line complications were reported in 7 practitioner administrations.

The Board understands that intravenous access may be complex in patients at end of life and may be outside the routine practice of participating practitioners. Difficulty establishing intravenous access prior to administration can be distressing to patients, families and practitioners.

**Recommendation 12:** Explore the establishment of a voluntary assisted dying cannulation service to support practitioners in circumstances where there are challenges in obtaining intravenous access and provide opportunities for continuing professional development for Coordinating and Administering Practitioners.

#### **Practitioner remuneration**

In 2022–23 the Board consulted with practitioners to document the minimum time and activities associated with each stage of the voluntary assisted dying process, including both contact (e.g., patient assessments, substance administration) and non-contact activities (e.g., documentation and completion of forms), estimating a minimum of 8.5 hours per patient who completes the request and assessment and administration process.

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

In the absence of adequate practitioner remuneration (via the Medicare Benefits Schedule or other funding mechanism), the Board has become increasingly aware of practitioners providing voluntary assisted dying as a private fee for service model.

As with all services provided by medical practitioners, the Board recognises that medical practitioners are free to determine reasonable fees that are reflective of the services they provide. The Board however is concerned that vulnerable patients at the end of life may experience inequity of access in being unable to afford out of pocket expenses for voluntary assisted dying.

**Recommendation 13:** Practitioner remuneration and service models to support voluntary assisted dying within the WA health system are progressed as a matter of priority to ensure that a patient's financial capacity is not a barrier to access to voluntary assisted dying.

56

#### **Grief and bereavement support**

In 2022–23, the Board reviewed grief and bereavement support available to patients and families impacted by voluntary assisted dying in Western Australia. Availability of specific voluntary assisted dying grief and bereavement resources and support services is limited. The review also identified the need for practitioner guidance and referral pathways for staff supporting families and caregivers after a voluntary assisted dying death.

A cohesive approach is required to support this emerging area of need, ensuring consistent and quality provision of grief and bereavement services to patients and families impacted by voluntary assisted dying.

Recommendation 14: The development of voluntary assisted dying grief and bereavement resources, practitioner guidance and referral pathways.

### Future focus

In the year ahead, the Voluntary Assisted Dying Board (the 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* (the Act).

#### Strategic Plan 2023 to 2026

58

The Voluntary Assisted Dying Board Strategic Plan 2023 to 2026 outlines how the Board will seek to fulfil its functions under the Act and make the most of its unique access to information, in support of the principles and intention of the Act, to ensure that voluntary assisted dying is available to all eligible Western Australians as a sustainable, person-centred, end-of-life choice. The Strategic Plan includes 6 strategic objectives:

- Contribute to community/health practitioner awareness and understanding of voluntary assisted dying, relevant to person, role, and stage of life.
- Identify conditions or obstacles that may act to:
  - prevent or impede lawful access to voluntary assisted dying in Western Australia
  - impact patient experience of voluntary assisted dying in Western Australia.
- Continue advocacy and oversight to ensure workforce is skilled, supported, and sustainable.
- Use a range of data sources to monitor the implementation and operation of voluntary assisted dying in Western Australia.
- Improve the utility and flow of information to support risk management, quality practice and planning.
- Build budget transparency, resources, and administrative structures to support responsive and accountable performance of Board functions.

Areas of focus in 2022–23 to support implementation of the strategic plan include:

- ongoing review of compliance and monitoring of cases
- advocacy in areas identified in recommendations and advice to the Minister of Health and Chief Executive Officer of the Department of Health on the improvement of voluntary assisted dying in Western Australia
- interjurisdictional engagement and consultation on issues that are common to all states and territories
- supporting research that aligns to the Board's strategic objectives and research focus areas of awareness, access and experience, and practitioner involvement in voluntary assisted dying
- ongoing stakeholder engagement, including regional engagement, to support the performance of the Board's functions
- monitoring feedback received on patient decision making capacity in relation to voluntary assisted dying.

**Appendices** 

## 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 2022–23 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 2022–23.

#### **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 2022–23 are included in the Department of Health's 2022–23 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

Volu	ntary Assisted Dying Act 2019 section 155(2)	Page reference
(a)	any recommendations that the Board considers appropriate in relation to voluntary assisted dying; and	53 – 57
(b)	any information that the Board considers relevant to the performance of its functions; and	47 – 52
(c)	the number of any referrals made by the Board under section 118(c); and	50
(d)	the text of any direction given to the Board under section 123(1) or 152(2); and	49
(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	49
(f)	statistical information that the Board is directed under section 152(2) to include in the report; and	49
(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.	6, 14, 18, 21, 24, 27, 29, 33, 34, 40, 41, 43, 44, 45, 52, 53, 55

## Appendix 2: Key contact list

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

Email: VADBoard@health.wa.gov.au

Website: <a href="https://ww2.health.wa.gov.au/Articles/U\_Z/Voluntary-assisted-dying-">https://ww2.health.wa.gov.au/Articles/U\_Z/Voluntary-assisted-dying-</a>

<u>board</u>

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

Email: VADcarenavigator@health.wa.gov.au

Phone: (08) 9431 2755

Website: https://ww2.health.wa.gov.au/Articles/U Z/Voluntary-assisted-dying/

Statewide-Care-Navigator-Service

#### **Statewide Pharmacy Service**

Email: StatewidePharmacy@health.wa.gov.au

Phone: (08) 6383 3088

Website: <a href="https://ww2.health.wa.gov.au/Articles/U\_Z/Voluntary-assisted-dying/">https://ww2.health.wa.gov.au/Articles/U\_Z/Voluntary-assisted-dying/</a>

Statewide-pharmacy-service

#### **End of Life care Program, Department of Health**

Email: EOLCare@health.wa.gov.au

Website: <a href="https://ww2.health.wa.gov.au/Articles/A\_E/End-of-Life-Care-Program">https://ww2.health.wa.gov.au/Articles/A\_E/End-of-Life-Care-Program</a>

or <a href="https://ww2.health.wa.gov.au/Articles/U">https://ww2.health.wa.gov.au/Articles/U</a> Z/Voluntary-assisted-dying

#### Join community of practice

Email: VADcarenavigator@health.wa.gov.au

Phone: (08) 9431 2755

## Appendix 3: List of tables and figures

Figure	Figure name	Page number
Figure 1	Number of practitioners who completed a First Assessment, Consulting Assessment and Practitioner Administration 2021 to 2023	14
Figure 2	Eligibility of patients undertaking First Assessment in 2022–23	20
Figure 3	Distribution of patient age at First Assessment in 2021–22 and 2022–23	21
Figure 4	Patients by primary diagnosis group in 2021–22 and 2022–23	22
Figure 5	Patient reason for accessing voluntary assisted dying 2022–23	22
Figure 6	Administration Decisions made 2021–22 and 2022–23	28
Figure 7	Voluntary assisted dying deaths by month and administration type in 2021–22 and 2022–23	32
Figure 8	Number of patient deaths by health region in 2021–22 and 2022–23	33
Figure 9	Oral/PEG/NG tube ingestion vs intravenous administration in 2021–22 and 2022–23	33
Figure 10	Number of days between First Request and death in 2021–22 and 2022–23	34
Figure 11	Voluntary assisted dying process stage of patients who died prior to administration of a voluntary assisted dying substance	35
Figure 12	Number of patient deaths by practitioner administration location in 2021 to 2023	37
Figure 13	Number of forms with a status of valid, void and revoked by health region submitted in 2021 to 2023	41

Table	Table name	Page number
Table 1	Number of participating practitioners by health region 2021 to 2023	14
Table 2	Number of participating practitioners by specialty type 2021 to 2023	15
Table 3	Number of First Requests made by health region in 2021–22 and 2022–23	18
Table 4	Palliative care information collected during First Assessment in 2021–22 and 2022–23	23
Table 5	Demographic characteristics of patients assessed as eligible for voluntary assisted dying in 2021–22 and 2022–23	24 – 25
Table 6	Day range between First Request and death in 2021–22 and 2022–23	34
Table 7	Length of time to death of patient via intravenous administration in 2021 to 2023	36
Table 8	Length of time to death of patient via assisted oral ingestion, assisted ingestion via PEG or NG tube in 2021 to 2023	36
Table 9	Number of patient deaths by practitioner administration location in 2021 to 2023	37
Table 10	Number of forms with a status of valid, void and revoked submitted in 2021–22 and 2022–23	40
Table 11	Statewide Care Navigator Service interactions in 2021 to 2023	43
Table 12	Regional Access Support Scheme Requests by health region in 2021–22	44
Table 13	Board Member term and meeting attendance 2022–23	49
Table 14	Section 155(2) of the <i>Voluntary Assisted Dying Act 2019</i> requires the inclusion of the following in the Annual Report	60

# Appendix 4: Voluntary assisted dying proposed national minimum dataset 2022–23 Western Australia<sup>24</sup>

Number of First Assessments		474									
A	18-39	40-49		50-59		60-69	70	)-79	80-89		≥90
Age group	11	5		40		112	15	53	105		48
Gender	Female		Male			Other/self-descril	bed				
Gender	197		277			0					
Residence	Major Cities of A	ustralia	tralia Inner Regional A		ralia	Outer Regional A	er Regional Australia		Remote Australia		Remote Australia
Residence	359		50 48		48		14		3		
Aboriginal and Torres Strait Islander origin		Aborigi	Aboriginal		Torres	THE CITAL ICIANNEL		original and To ait Islander	rres	No	
	•	6	6		0	0 0				468	
Highest level of education co	ompleted	Did not complete secondary school					mpleted post-s ucation	econdary	Not repo	orted	
•	•	15		256		20	2		1		
lles of intermuster	Yes	No	)								
Use of interpreter	6	46	88								
Place of birth	Australia	0	verseas								
	287	18	187								

<sup>24</sup> Data in the appendix represents the number of valid, void and revoked forms submitted to the Voluntary Assisted Dying Board at each respective stage of the voluntary assisted dying process. As some patients may have completed a process step more than once in the period, this data does not represent the number of unique people completing each stage of the voluntary assisted dying process (excluding patient deaths).

62

**Implementation** 

Datat	from	Firet A	Assessme	nt l	Forms
Dala	IIIIII	ГП 5 L <i>F</i>	<del>1</del> 556551116	ווווו	LOI III 2

Life limiting condition		Cancer		Neurological		Respiratory		Other
Life limiting condition		319		67		37		51
Palliative care	Yes		No					
	384		90					
Practitioner type	General Practition	ner	Specialist	Other				
	0.4		0.4					

0

21

#### Data from Administration Decision and Prescription Forms

24

Administration route	Self-Administration	Practitioner Administration
	49	305

#### Data from Authorised Supply Forms

Number of substance supplies	Self-Administration	Practitioner Administration		
Supplies	46	237		

#### Data from Notification of Death and Practitioner Administration Forms

Voluntary assisted dying deaths			5		
Manner of death	Self-administration		Practitioner administration	Substance not administered	
	45		210		111

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