Voluntary Assisted Dying in South Australia

Quarterly Report | 1 May to 30 June 2023

Message from the Presiding Member of the Voluntary Assisted Dying Review Board

On behalf of the Voluntary Assisted Dying Review Board, I am pleased to present the second Quarterly Report on voluntary assisted dying in South Australia covering the period 1 May to 30 June 2023. The shorter reporting period for this report will ensure future quarterly reporting can be brought into alignment with standard quarterly reporting timeframes.

As this report shows, there has been a gradual increase in the number of people accessing voluntary assisted dying over these two months in comparison to the first quarterly report. An annual voluntary assisted dying activity report in November will provide a greater perspective on patterns of access and service delivery in South Australia over time.

By continuing to provide this detailed account of voluntary assisted dying activity in South Australia, we aim to help our community understand how voluntary assisted dying is being accessed and utilised in South Australia and to support discussion. We also have the opportunity to learn from the experiences of other states who have preceded us so that we can continue to deliver an equitable, high quality and person centered service for eligible South Australians.

The Board acknowledges the recent story of a young woman who chose to share her journey about accessing voluntary assisted dying with the community. This story shed light on the importance of choice at end of life and prompted a valuable public conversation about voluntary assisted dying in South Australia.

We continue to hear through feedback provided to the Board, about the role voluntary assisted dying plays in alleviating suffering for individuals and the peace of mind it can offer to the bereaved. The Board offers heartfelt condolences to all those grieving for their loved ones.

The Board extends sincere gratitude to all those who continue to play a vital role in operation of voluntary assisted dying in South Australia. Your contributions have been instrumental in shaping this report and shaping the future of end of life care in South Australia.



ASSOCIATE PROFESSOR MELANIE TURNER
Presiding Member
On behalf of the Voluntary Assisted Dying Review Board



Feedback from patients, families, and the community

Medical practitioners, Pharmacists, Care Navigators and Voluntary Assisted Dying Liaison Officers continue to provide essential support to patients and families every day, ensuring that people have access to all the information and support they need to make informed decisions about their end of life care. Feedback received from patients and families continues to demonstrate the quality of service provision and support being provided:

'The VAD Liaison nurse was reassuring, knowledgeable, confident, and professional, but also very down to earth, human, and sensitive to XX's needs. It felt like her presence created a safe space for us and the enormity of the situation.'

'The instructions and pharmacist's guidance were excellent, caring, and helpful. The process seemed simple, straightforward, and effective'

'I just wanted you to know that I have found this whole process so liberating. I want to congratulate the whole team on how beautifully sensitive, respectful, and non-judgmental the whole process has been'

'From the initial doctor's visit and request for VAD, my experience of the process was highly supportive, clear, and thorough. The doctor worked his way through the assessment process in a manner that enabled my full understanding of just how the pathway would unfold in a clear and sensitive manner.'

'The support given by the Care Navigator Service and the ready availability, compassion and care they consistently showed worked well'

'I just want to say how grateful we all are that dad could leave this world on his terms. I just want to preach from the hilltops, he was 94 and he died with dignity'



Voluntary assisted dying in the media

There has been a significant amount of media coverage regarding voluntary assisted dying during this reporting period, firstly as a result of the release of the first quarterly report on 7 June 2023 and then surrounding the story of a young person who chose to share her story in choosing to access voluntary assisted dying. Media coverage of both of these events has been supportive of all those involved in both the delivery of voluntary assisted dying and of patients and families. The increased attention and focus have provided an opportunity to reflect on how best to inform the community regarding this sensitive and personal topic.

The Voluntary Assisted Dying Review Board have considered this increased media attention and its potential impact on those involved in voluntary assisted dying. Maintaining patient, family and staff confidentiality while reporting on voluntary assisted dying in the media is of paramount importance. This facilitates the upholding of ethical standards and respects individual privacy around decisions related to voluntary assisted dying including the timing and place of a person's death. Striking the right balance to achieve respectful informative reporting is key to ensuring the wellbeing of those involved in the voluntary assisted dying process.

Voluntary assisted dying terminology

In recent media the use of the term euthanasia has occurred in relation to the voluntary assisted dying process. The use of the term voluntary assisted dying is generally considered preferable to the term euthanasia. Voluntary assisted dying emphasises the aspect of choice and autonomy in end-of-life decisions, highlighting that the decision to pursue such an option is made willingly by the individual. This terminology recognises that the person seeking assistance wishes to maintain control over their own life and death, while also acknowledging the involvement of healthcare professionals in providing the necessary support.

The term euthanasia has been known to carry connotations of a more passive act, where the decision and action to end a person's life are solely made by others. By using the term voluntary assisted dying, the focus shifts towards the individual's agency and the importance of compassionate support, fostering a more compassionate and informed discussion around this sensitive topic.

Feedback about voluntary assisted dying

The Review Board is grateful for the feedback and personal reflections that have been shared since the commencement of voluntary assisted dying and extends sincere thanks for the time and consideration taken to compose feedback and for the depth of insights shared. The feedback is a powerful validation of the effort of so many to provide this service to the community at end of life. The Board welcomes further feedback from patients, families, medical practitioners, and other health professionals. If you have been involved in supporting a person on the voluntary assisted dying pathway and would like to submit a personal reflection form please visit the SA Health webpage.

Ensuring the independence of the Voluntary Assisted Dying Review Board

Members of the Voluntary Assisted Dying Review Board are not eligible to participate in the Voluntary Assisted Dying pathway as either a Coordinating or Consulting medical practitioner or to perform the role of witness or contact person for a person on the voluntary assisted dying pathway. This helps to ensure that the Review Board can maintain an independent position when reviewing voluntary assisted dying activity in South Australia.

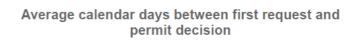


Voluntary Assisted Dying Permits issued

Permits issued by type

People who have had a permit issued

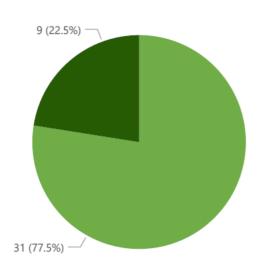
40



27.84

Percentage of permits issued within the prescribed period (3 business days)

100%



 $lue{f O}$ Self-Administration $lue{f O}$ Practitioner Administration

Between 1 May and 30 June 2023:

- A total of 40 people were issued with a voluntary assisted dying permit by the Chief Executive of the
 Department for Health and Wellbeing. 31 permits were for self-administration of the voluntary assisted
 dying substance and 9 were for practitioner administration of the voluntary assisted dying substance.
- On average 27.84 days elapsed between a person making a first request to access voluntary assisted dying and receiving an outcome regarding an application for a voluntary assisted dying permit.
- 100% of permit applications to the Chief Executive of the Department for Health and Wellbeing had a
 decision made within 3 business days as prescribed under Section 16 of the Voluntary Assisted Dying
 Regulations 2022.

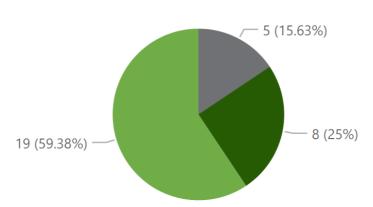
Deaths

Between 1 May and 30 June 2023, a total of 32 people who were the subject of a voluntary assisted dying permit died. Of these:

- 19 people died as a result of self-administration of the voluntary assisted dying substance
- 8 people died as a result of practitioner administration of the voluntary assisted dying substance
- 5 people died without taking the substance.



Deaths

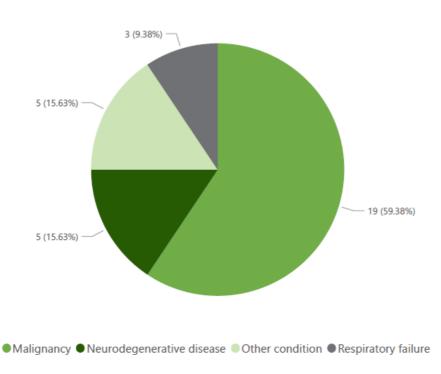


■ Patient did not administer substance ■ Practitioner Administration ■ Self-administration

Of the 32 people who died who were the subject of a voluntary assisted dying permit between 1 May and 30 June 2023:

- 19 people had cancer as the disease, illness, or medical condition for which they were eligible for voluntary assisted dying.
- 5 people had a neurodegenerative disease, as the disease illness or medical condition for which they were eligible for voluntary assisted dying.
- 3 people had respiratory failure as the disease, illness, or medical condition for which they were eligible for voluntary assisted dying.

Underlying disease, illness or medical condition

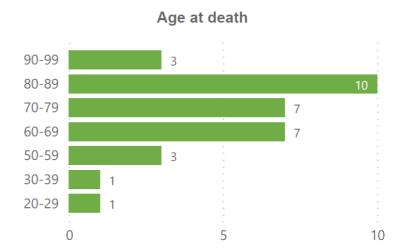


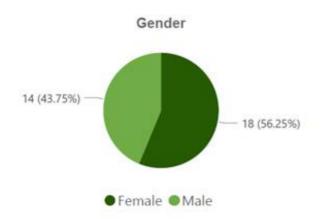


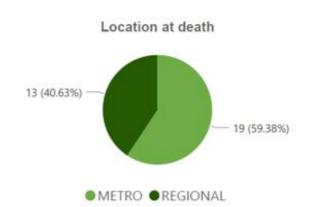
Demographics

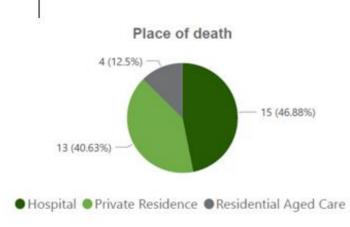
Of the 32 people who died between 1 May and 30 June 2023:

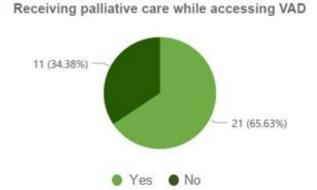
- 20 were aged over 70 years at the time of their death
- 18 were female and 14 were male
- 19 lived in metropolitan Adelaide and
 13 lived in regional South Australia
- 13 people died at home, 15 people died in a hospital and 4 people died in a residential aged care facility
- 21 people were receiving a palliative care service while accessing voluntary assisted dying.













Medical practitioners

Since the commencement of voluntary assisted dying in South Australia a total of 112 medical practitioners have registered to undertake the mandatory practitioner training to be able to deliver voluntary assisted dying. Of these, 73 percent reside in metropolitan Adelaide with the remaining 27 percent in regional South Australia.

Of the 112 practitioners who registered to undertake the mandatory training, 59 percent have completed the training and are eligible to deliver voluntary assisted dying in South Australia. Of these 74 percent reside in metropolitan Adelaide and 26 percent reside in regional South Australia.

The representation of medical practitioners across metropolitan and regional areas closely reflects South Australia's population distribution with approximately 30 percent of people residing in a regional area.

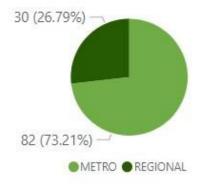
Registered practitioners

112

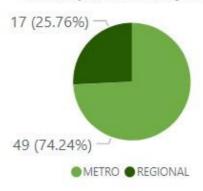
Trained practitioners

66





Trained practitioners by location



In order to access voluntary assisted dying in South Australia, a person must have their eligibility for voluntary assisted dying verified by two independent medical practitioners who have both undertaken the mandatory training.

The medical practitioner who accepts a person's first request for voluntary assisted dying is called the Coordinating Practitioner, the medical practitioner who accepts a referral from the Coordinating Practitioner is called the Consulting Practitioner.

A medical practitioner who has undertaken the mandatory training is eligible to undertake either role. In addition, not all registered medical practitioners are actively engaged in delivering voluntary assisted dying services.

In addition to having eligibility for voluntary assisted dying assessed by both the Coordinating and Consulting Practitioner, there are a group of patients who will also require a specialist opinion from an additional medical practitioner with specific expertise in the persons disease, illness or condition, to assess the persons prognosis.



A specialist providing an opinion to the Coordinating or Consulting Practitioner does not need to have undertaken the mandatory voluntary assisted dying training and are able to base their opinion on recent clinical knowledge of the patient for whom the opinion is being sought.

For the period 1 May – 30 June 2023:

- 27 of the 66 trained medical practitioners accepted a first request from a person seeking access to voluntary assisted dying becoming the Coordinating Practitioner for that person.
- 31 of the 66 trained medical practitioners accepted a referral from a Coordinating Practitioner to be a Consulting Practitioner.

Number of Coordinating Practitioners

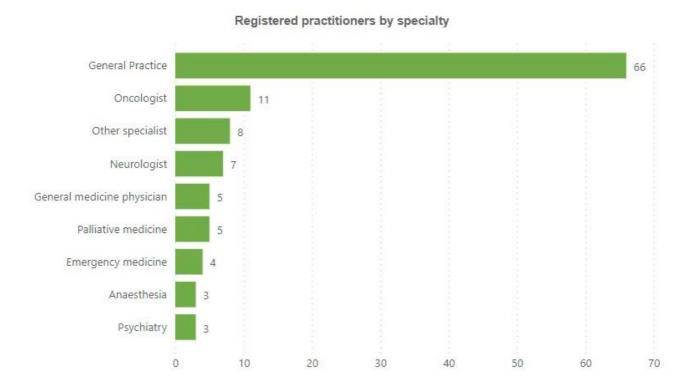
Number of Consulting Practitioners

27

31

Of the 112 medical practitioners who registered to complete the mandatory training to deliver voluntary assisted dying in South Australia, 66 are General Practitioners with the remaining 46 from a range of medical specialties including Oncology, General medicine, Neurology, Palliative medicine, Emergency medicine, Anaesthesia and Psychiatry.

The high representation of General Practitioners reflects the important role that GPs play in end of life care planning for patients living with a life limiting illness.





Feedback

If you would like to provide feedback to the Voluntary Assisted Dying Review Board, please email us at: <u>Health.VADReviewBoard@sa.gov.au</u>.

For more information

Health Services Programs Branch Department for Health and Wellbeing

<u>Health.VoluntaryAssistedDying@sa.gov.au</u> <u>Voluntary Assisted Dying in South Australia | SA Health</u>

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