# **Voluntary Assisted Dying in South Australia**

## Quarterly Report | 1 April to 30 June 2024

## 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 6<sup>th</sup> quarterly report on voluntary assisted dying activity in South Australia covering the period 1 April to 30 June 2024.

During this reporting period we have seen a significant amount of media activity relating to a person in custody accessing voluntary assisted dying. The Review Board acknowledges that access to voluntary assisted dying for people who have been charged with or committed a crime causes concern among some members of our community. Whilst a range of views is understandable, the *Voluntary Assisted Dying Act 2021* does not give anyone the ability to prevent a person in custody, who meets the eligibility criteria, from accessing voluntary assisted dying. This is consistent with everybody's human right to healthcare including those who are in custody.

Data for this reporting period continues to show a gradual increase in applications for voluntary assisted dying and in deaths from administration of the VAD substance consistent with patterns seen in other jurisdictions and internationally. It is pleasing to note that we continue to see over 80 percent of VAD applicants receiving palliative care whilst they are on the voluntary assisted dying pathway. I would especially like to acknowledge the model of care in the Northern Adelaide Local Health Network that refers all their VAD patients to the Northern Adelaide Palliative Care Service to ensure palliative care support is available to all patients on the VAD pathway.

Palliative care is a part of end of life care for many people and it aims to improve quality of life for people with a life-limiting illness and their families and carers. This report includes additional information about palliative care. Voluntary assisted dying provides an additional end of life choice for eligible people. For people accessing voluntary assisted dying, palliative care can continue to actively support them with their symptom management and psychosocial care.

The Review Board acknowledges those individuals who have chosen to access the voluntary assisted dying pathway and offer heartfelt condolences to the bereaved. The Board also extends sincere gratitude to all those who continue to play a vital role in operation of voluntary assisted dying in South Australia. Your contributions are instrumental in shaping 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

Participating Medical practitioners, Pharmacists, Care Navigators, Voluntary Assisted Dying Liaison Officers, and volunteers 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, families and medical practitioners continues to demonstrate the quality-of-service provision and support being provided and is useful to inform service improvements:

I was so impressed by the way the system was put together and the people who interacted at every stage with us. I was really impressed by all of the people involved. They really did know their areas of expertise but at the same time they were so compassionate but made it easy to gain both information and support from them.

The final words she said as she was losing consciousness were:

'Thank you, thank you thank you'

While I am very happy that Mum was able to access VAD, it has been a bit harder for me to process than I thought it would be probably because the day began so happily with Mum having a nice time with those she loved, and then the day ended with her having passed away and her body being collected. I wonder if, for me, I may have felt more comfortable if Mum was in the hospital as then it may have seemed more clinical, but the process was not about me at all, and I am very glad that Mum got what she wanted. Having thought about it at length over the last month, I think my slight discomfort with the process potentially just stems from our societal avoidance of death and treating it as a clinical condition rather than the natural process it really is.

It was then such a peaceful and quick death for someone who had been suffering such emotional pain and distress. Her family were all present and we felt such relief for her and tremendous gratitude that she was able to use VAD. It gave her peace of mind knowing she had this option. 'I believe that this whole process from the time we were involved was of the highest standard I have witnessed in 20 years working in aged care. The dignity and respect it affords the person cannot be truly understood and no words can capture the sense of calm and control that the person felt. As a healthcare worker I am privileged to have been a small part of this journey for xx, to have sat with him and offered comfort is something that I will forever be thankful for.'





## Information and updates

#### Accessing Palliative Care and Bereavement Support in South Australia

Palliative care plays a vital role at the end of life for many Australians including those accessing the VAD pathway. Yet many people are not sure what it is. From the time of diagnosis, palliative care helps people of all ages with a life-limiting illness live their life fully and comfortably.

Palliative care addresses physical symptoms as well as emotional, social, and spiritual concerns. The primary goals of palliative care are to control symptoms, maximise function, maintain quality of life and provide comfort. Through palliative care, family, friends and carers can also receive practical and emotional support in their caring role and in grief and bereavement.

#### When can I access palliative care?

Palliative care is not just for the last days or weeks of life. It can be provided at any time in a person's illness depending on their needs including when they are on the VAD pathway. Palliative care can be provided from the time of diagnosis alongside active treatments and focuses on improving symptom control and quality of life, while supporting the emotional wellbeing of family and friends.

#### Who provides palliative care?

Palliative care is provided by many kinds of healthcare professionals and can be provided in the community, a home, hospital, aged care facility, or other healthcare facility. In a hospital setting it is provided by doctors, palliative specialists, nurses, pharmacists and allied health professionals.

In the community the palliative care team might include your general practitioner, community and aged care nurses, pharmacists, visiting allied health professionals, care workers and support workers. Family, friends, and neighbours may also provide care and support.

Specialist palliative care teams work in a consultative role with general practitioners and other health care providers when patient's needs cannot be met exclusively by primary care teams.

In South Australia, a person may be eligible for referral to specialist palliative care services if they have a progressive, life limiting illness and they or their decision maker, is aware of, understands and has agreed to a palliative care referral.

Referrals can be made by medical practitioners, other health professionals and the individual or family members/carer. Referrals for people living in the community (that is, home or residential care), or people requiring an outpatient clinic appointment, can be made by faxing a completed <u>Palliative</u> <u>Care Referral form</u> to your local palliative care service.

#### **Palliative Care Connect**

Palliative Care Connect was launched in late 2023 and provides information and links to palliative care and bereavement supports for people with life-limiting illnesses and their family, friends, and carers, as well as health and aged care professionals.

Palliative Care Navigators, available via a phone line, provide a link between consumers, primary health networks, specialist palliative care services, and community-based organisations, ensuring a seamless network of care provision that empowers individuals to make choices aligned with their culture and preferences.



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Palliative Care Navigators also support general practitioners and other healthcare professions, including those who work in palliative care units, acute care and aged care services to organise and link people to appropriate palliative care, supports or services including community nursing, My Aged Care and Commonwealth Home Support Packages.

Other Palliative Care Connect services include: specific palliative care navigation services for Aboriginal people and those living in regional areas; statewide bereavement navigation and support; a consumer friendly website <u>www.palliativecareconnect.com.au</u>; and volunteer support through the <u>Palliative Care Volunteering SA</u> project.

Palliative Care Connect has been funded through a \$7.27 million grant from the Australian Government and in the first 6 months of going live provided information and links to palliative care and bereavement services for over 350 people.

Feedback on the service highlights users appreciate the Navigators' empathetic approach, timeliness of service brokerage and tailoring of information to their level of understanding and needs.

#### To talk to someone about palliative care and bereavement supports:

Call 1800 725 548 (PALLI8) Monday to Friday 8.30am to 4.00pm or Email <u>health.pcnavigation@sa.gov.au</u> or <u>request a call back</u> via the online form.

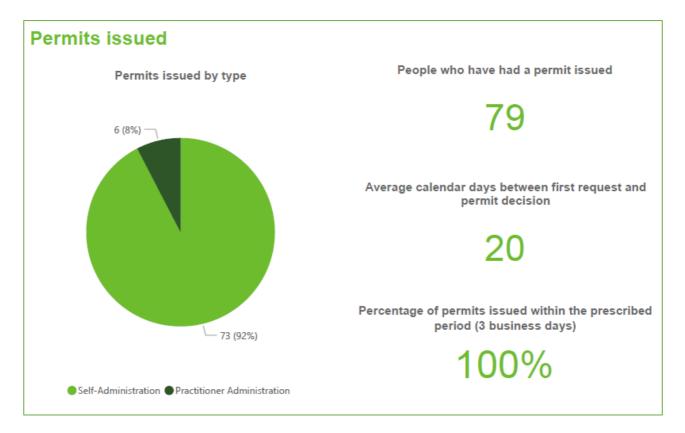




## Voluntary assisted dying permits issued 1 April – 30 June 2024

Between 1 April and 30 June 2024:

- A total of 79 people were issued with a voluntary assisted dying permit.
- Of these, 73 (92%) permits were for self-administration of the voluntary assisted dying substance and 6 (8%) were for practitioner administration of the substance.
- On average, 20 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, DHW had a decision made within 3 business days as prescribed under Section 16 of the *Voluntary Assisted Dying Regulations* 2022.



## **Deaths**

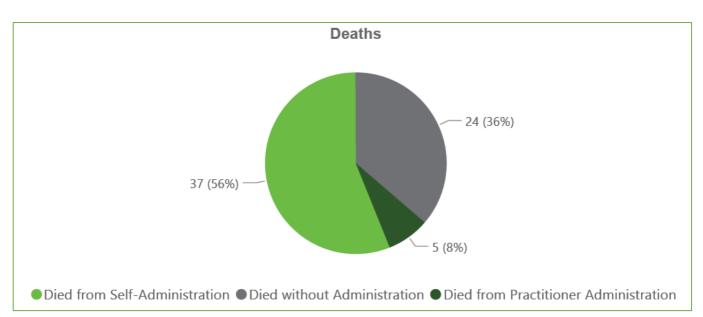
Between 1 April and 30 June 2024, a total of 66 people who were the subject of a voluntary assisted dying permit died. Of these:

- 37 (56%) people died as a result of self-administration of the voluntary assisted dying substance
- 5 (8%) people died as a result of practitioner administration of the voluntary assisted dying substance
- 24 (36%) people died without administration of the substance



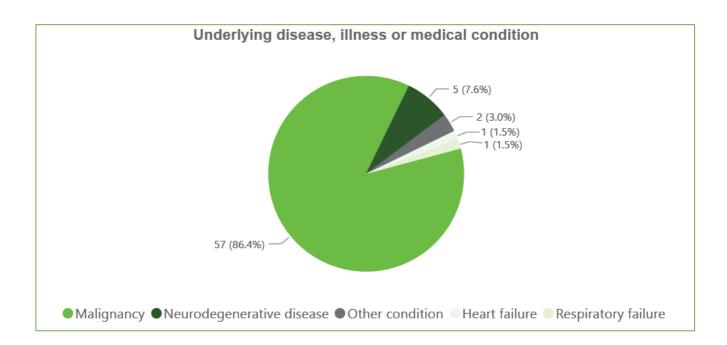
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Of the 66 people who died who were the subject of a voluntary assisted dying permit between 1 April and 30 June 2024:

- 57 (86%) people had cancer as the disease, illness, or medical condition for which they were eligible for voluntary assisted dying.
- 5 (8%) people had a neurodegenerative disease, as the disease illness or medical condition for which they were eligible for voluntary assisted dying.



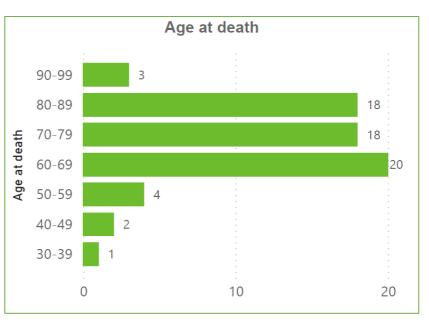




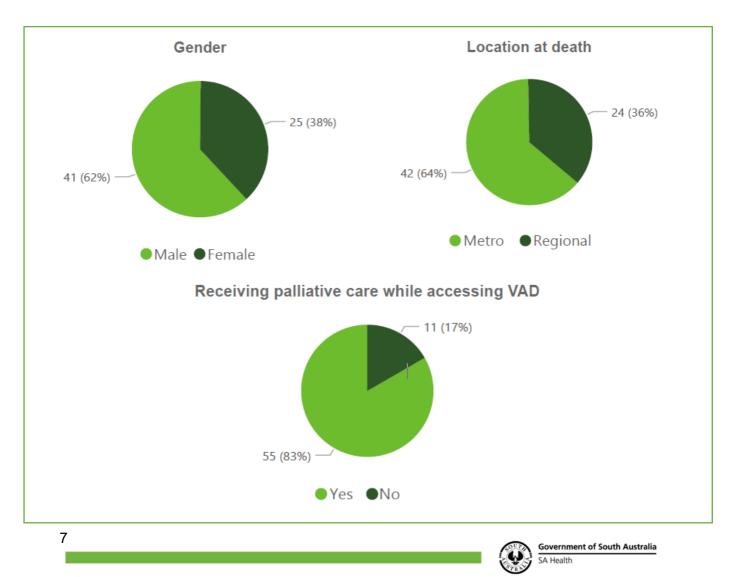
## **Demographics**

Of the 66 people who died who were the subject of a voluntary assisted dying permit between 1 April and 30 June 2024:

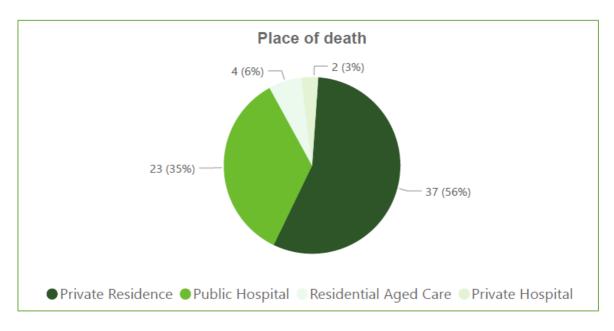
- 59 (93%) were aged 60 years or older at the time of their death.
- 25 (38%) were female and 41 (62%) were male (noting the figure for males is 56% for the 12 months to 30 June).
- 42 (64%) lived in metropolitan Adelaide and 24 (36%) lived in regional South Australia.



- 55 (83%) were receiving palliative care while accessing voluntary assisted dying.
- 37 (56%) died in private residence, 23 (35%) died in a public hospital, 4 (6%) died in a residential aged care facility and 2 (3%) died in a hospice or palliative care unit.



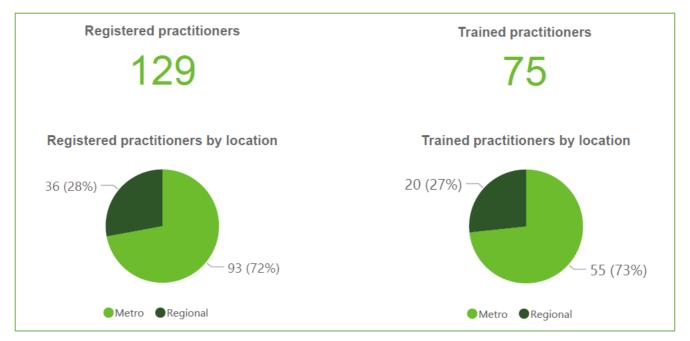




## **Medical practitioners**

Since the commencement of voluntary assisted dying in South Australia a total of 129 medical practitioners have registered to undertake the mandatory practitioner training to be able to deliver voluntary assisted dying. Of these, 93 (72%) reside in metropolitan Adelaide with the remaining 36 (28%) in regional South Australia.

Of the 129 practitioners who registered to undertake the mandatory training, 75 (58%) have completed the training and are eligible to deliver voluntary assisted dying in South Australia. Of those who have completed the training, 55 (73%) reside in metropolitan Adelaide and 20 (27%) reside in regional South Australia.



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

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a regional area. We appreciate the work of all of our trained medical practitioners and in particular thank those who have travelled a distance to regional areas to support patients on the VAD pathway where this has been required.

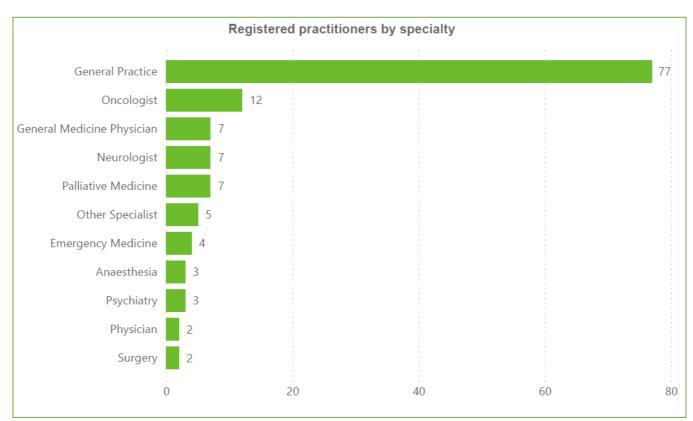
For the period 1 April to 30 June 2024:

- 43 of the 75 trained medical practitioners accepted a first request from a person seeking access to voluntary assisted dying becoming the Coordinating Practitioner for that person.
- 48 of the 75 trained medical practitioners accepted a referral from a Coordinating Practitioner to be a Consulting Practitioner.



Of the 129 medical practitioners who registered to complete the mandatory training to deliver voluntary assisted dying in South Australia, 77 (60%) are General Practitioners with the remaining 52 (40%) 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 and valued 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>.

**Note:** Data for this reporting period may be updated in future reporting as a result of voluntary assisted dying death notifications for this reporting period that are received after publication of this report.

## 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> ISSN 2981-8052

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