Voluntary Assisted Dying in South Australia

Quarterly Report | 1 October to 31 December 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 fourth quarterly report on voluntary assisted dying in South Australia covering the period 1 October to 31 December 2023.

The release of this quarterly report coincides with the one year anniversary of the commencement of Voluntary Assisted Dying Legislation in South Australia on 31 January 2023.

Feedback from patients, families, clinicians and the community, and review of each completed voluntary assisted dying pathway to date, provides me with confidence that voluntary assisted dying in South Australia is being carried out in accordance with the *Voluntary Assisted Dying Act 2021* and is providing relief of suffering and greater choice at end of life as intended.

The Review Board is continuing to work closely with staff within SA Health and other stakeholders to improve access to and awareness of voluntary assisted dying for all eligible South Australians. This is being achieved through development of patient centred models of care and resources, successful establishment of a volunteer witnessing program and ongoing engagement with medical practitioners, SA Health staff, private hospitals, community groups and organisations across South Australia.

Plans for 2024 include several regional forums to raise awareness of and respond to community questions about voluntary assisted dying and other end of life matters; contributing to national research into voluntary assisted dying; and a Voluntary Assisted Dying memorial service to be held in April 2024 to provide an opportunity for family, friends and loved ones to come together in remembrance.

The 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:

I had the privilege yesterday of sitting with XXX as she completed the VAD process. XXX has been a general practice patient of mine for about fifteen years and has been struggling with her disease for much of that time.

Before she died, she expressed her gratitude for the VAD process. She valued the control it gave her over her symptoms and her dignity and the capacity to relieve her suffering at a time and place of her choosing with her family and friends present. She spoke of the surreal experience of experiencing her last sunset and her last sunrise and the last time she would hear the rain on the roof.

She was in a hospital bed in the lounge room with the window open into the back garden. Her granddaughter was playing outside. She smiled as she listened to the native birds audible through the open window. Her husband, son, daughter in law and three of her closest friends were with her.

She took the VAD medication and was asleep in less than five minutes. A further ten minutes later she stopped breathing. At about this moment there was a short burst of rain outside which everyone present felt was significant.

It was a peaceful death – it was calm, controlled and I believe overall was a positive experience for everyone present.

This is such a contrast to my own personal and professional experience of death. I am extremely grateful to be able to participate with all of you in providing this service to people who choose it.

Feedback received from a Medical Practitioner

The word 'ethical' keeps coming to mind when I think of our family's interaction with the VAD process and the Care Navigator Service. I think that best encapsulates the mix of principle, professionalism and kindness. Thank you.

Feedback from family member

My daughter at no time felt any pressure. She was very clear about her agreement and this wonderful option to resolve the pain and change in her life was a process filled with compassion, clarity, professionalism, and she was in control every step of the way. This gives us as a family relief that she did this her way, and she went so peacefully

Feedback from mother of a VAD patient

I wanted to thank you, you are all so wonderful and caring. At such a difficult time you were all amazing. Thank you again for your kindness and care.

Feedback from daughter of VAD patient



News and updates on voluntary assisted dying

Grief and bereavement after voluntary assisted dying

When a life ends through voluntary assisted dying, family members and friends may experience grief that is complicated by the circumstances of their loved one's death. Family and friends may talk about how thankful and relieved they feel knowing their loved one was able to end their suffering on their own terms; but like any death, when a life ends through voluntary assisted dying, there may be complicated emotions, and the complexities of grieving after a voluntary assisted death aren't always understood.ⁱ <u>GriefLink</u> is an online resource that provides helpful information for people who are dealing with grief caused by the death of someone close to them, and for those who are supporting them.

In addition, SA Health provides grief and bereavement support to individuals and families whilst they are on the voluntary assisted dying pathway and is currently trialing bereavement support groups targeted to people who have been bereaved as a result of voluntary assisted dying. Small groups are facilitated by a specialist grief and bereavement counsellor and provide a safe space to connect and share with others who can relate to the challenges of loss and grief. Groups have a focus on personal sharing and discussion of helpful strategies.

The SA Voluntary Assisted Dying Care Navigator Service can provide information regarding accessing bereavement support in relation to voluntary assisted dying. For further information about bereavement supports available or to participate in an upcoming group please contact the Care Navigator Service by telephone at 0403087390 or by email at Health.VADCareNavigators@sa.gov.au.

Community engagement

Ms Helen Walker, Deputy Presiding Member and Mr John Dawkins, Member of the Voluntary Assisted Dying Review Board recently visited Port Elliot to participate in two community forums on voluntary assisted dying held on 15 November 2023. Over 40 community members were in attendance. The forums provided the opportunity for participants to learn about voluntary assisted dying legislation and the voluntary assisted dying pathway and to have their questions answered by members of the Board and the Voluntary Assisted Dying Operations team. The forum generated meaningful discussion and received positive feedback.

Following on from this event, key VAD leaders will host several regional forums focusing on end of life across regional South Australia throughout 2024.

In addition, the first annual VAD Memorial service will be held in Adelaide in April 2024. This event is intended to provide an opportunity for family, friends and loved ones of those who have died on the VAD pathway to come together in remembrance. To express your interest in receiving further information about this event please email: <u>Health.VADReviewBoard@sa.gov.au</u>.





Advance Care Directives

The Advance Care Directives (Review) Amendment Bill 2022 passed the South Australian Parliament on 30 November 2023, paving the way for several important enhancements to the operation of the Advance Care Directives Act 2013. An Advance Care Directive (ACD) is an important legal document that allows people over the age of 18 years to:

- write down their wishes, preferences and instructions for future health care, end of life, living arrangements and personal matters and/or
- appoint one or more Substitute Decision-Makers to make these decisions on their behalf when they are unable to do so themselves.

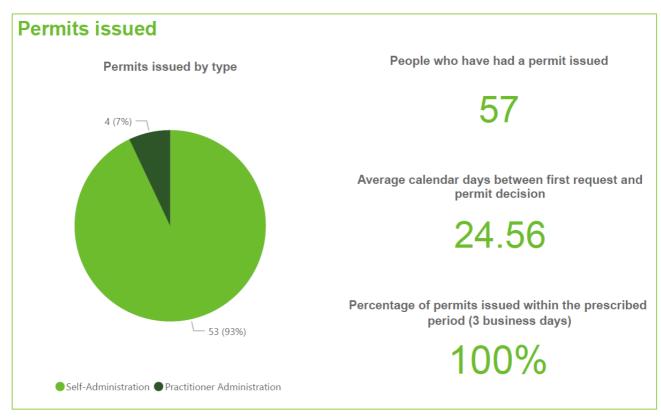
Whilst a person can make their wishes in relation to voluntary assisted dying known in an ACD, under the Voluntary Assisted Dying Act 2021, an ACD can not constitute a request for VAD. This is because a person can only be eligible for VAD under the Act if they have decision making capacity. Information about Advance Care Directives including the new Advance Care Directive DIY Kit is available on the <u>SA Health webpage</u>.

Translated information about voluntary assisted dying

To improve access to VAD for speakers of languages other than English, a 2 page fact sheet titled Voluntary Assisted Dying has been translated into 12 additional languages including Arabic, Chinese, Greek, Gujarati, Hazargi, Italian, Nepali, Persian, Punjabi, Spanish, Tagalog and Vietnamese. The fact sheet provides clear information about eligibility, the steps on the pathway and where to get more information or support. Fact sheets on voluntary assisted dying can be accessed on the <u>SA Health website</u>.



Voluntary assisted dying permits issued 1 October – 31 December 2023



Between 1 October and 31 December 2023:

- A total of 57 people were issued with a voluntary assisted dying permit.
- Of these, 53 permits were for self-administration of the voluntary assisted dying substance and 4 were for practitioner administration of the substance.
- On average 25 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

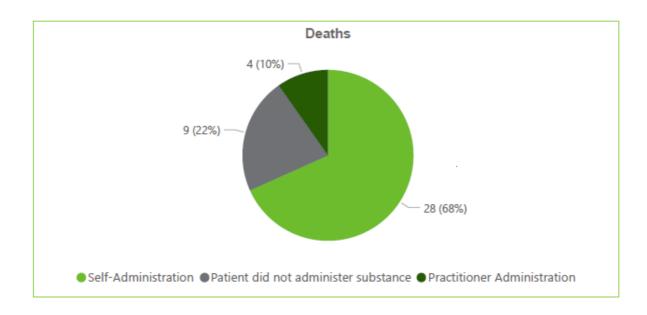
Between 1 October and 31 December 2023, a total of 41 people who were the subject of a voluntary assisted dying permit died. Of these:

- 28 people died as a result of self-administration of the voluntary assisted dying substance
- 4 people died as a result of practitioner administration of the voluntary assisted dying substance
- 9 people died without taking the substance



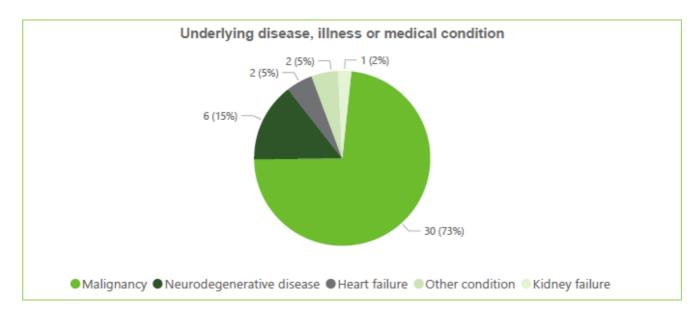
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Of the 41 people who died who were the subject of a voluntary assisted dying permit between 1 October and 31 December 2023:

- 30 people had cancer as the disease, illness, or medical condition for which they were eligible for voluntary assisted dying.
- 6 people had a neurodegenerative disease, as the disease illness or medical condition for which they were eligible for voluntary assisted dying.



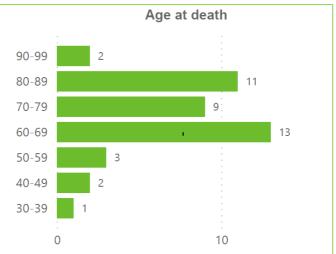


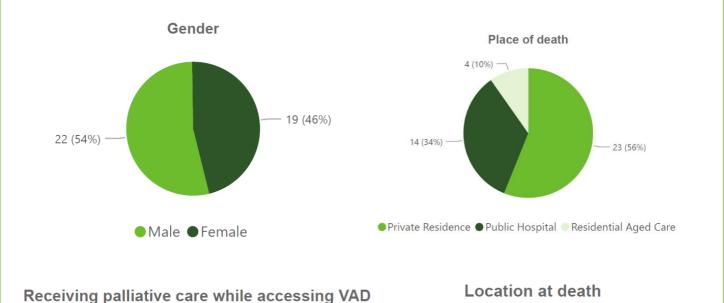


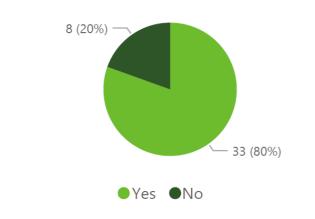
Demographics

Of the 41 people who died who were the subject of a voluntary assisted dying permit between 1 October and 31 December 2023:

- 35 (85%) were aged over 60 years at the • time of their death
- 19 were female and 22 were male •
- 68 percent lived in metropolitan Adelaide and • 32 percent lived in regional South Australia
- 23 died in private residence, 14 died in a • public hospital, 4 died in a residential aged care facility
- 80 percent were receiving palliative care • while accessing voluntary assisted dying.

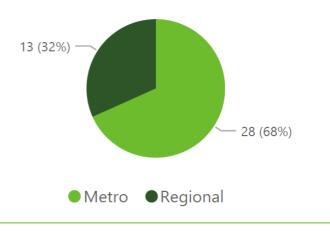






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Location at death



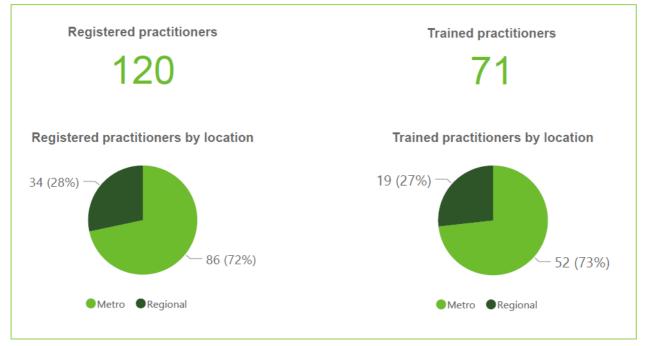




Medical practitioners

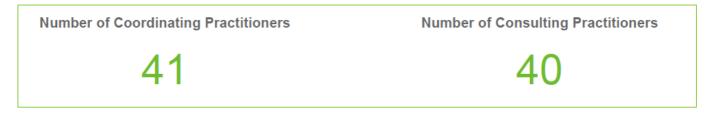
Since the commencement of voluntary assisted dying in South Australia a total of 120 medical practitioners have registered to undertake the mandatory practitioner training to be able to deliver voluntary assisted dying. Of these, 86 (72%) reside in metropolitan Adelaide with the remaining 34 (28%) in regional South Australia.

Of the 120 practitioners who registered to undertake the mandatory training, 71 (60%) have completed the training and are eligible to deliver voluntary assisted dying in South Australia. Of these 52 (73%) percent reside in metropolitan Adelaide and 19 (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 a regional area.



For the period 1 October to 31 December 2023:

- 41 of the 70 trained medical practitioners accepted a first request from a person seeking access to voluntary assisted dying becoming the Coordinating Practitioner for that person.
- 40 of the 70 trained medical practitioners accepted a referral from a Coordinating Practitioner to be a Consulting Practitioner.

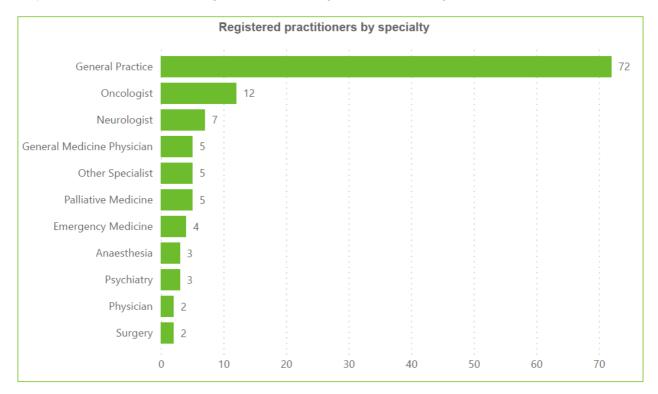






Of the 120 medical practitioners who registered to complete the mandatory training to deliver voluntary assisted dying in South Australia, 72 are General Practitioners with the remaining 48 from a range of medical specialties including Oncology, General medicine, Neurology, Palliative medicine, Emergency 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>.

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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ⁱ Grief Australia, 2022 The grief of families and friends after a voluntary assisted death, available online at: <u>https://www.grief.org.au/ga/Content/Information-Sheets/Grief of Families and Friends After a Voluntary Assisted Death.aspx</u>

