

Written evidence submitted by Go Gentle Australia (ADY0184)

While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal care. – Palliative Care Australia

Dad didn't choose death. Dad chose life over and over again. He chose it when he knew he would have his sides ripped out. He chose it when he knew he would have chemotherapy that would make him sick for another six months. He chose life, he chose life, he chose life. And when life was no longer a choice, he decided to die on his own terms. - Katie Harley, whose father Phil, 70, metastatic bowel cancer, elected to have an assisted death in Victoria in 2019.

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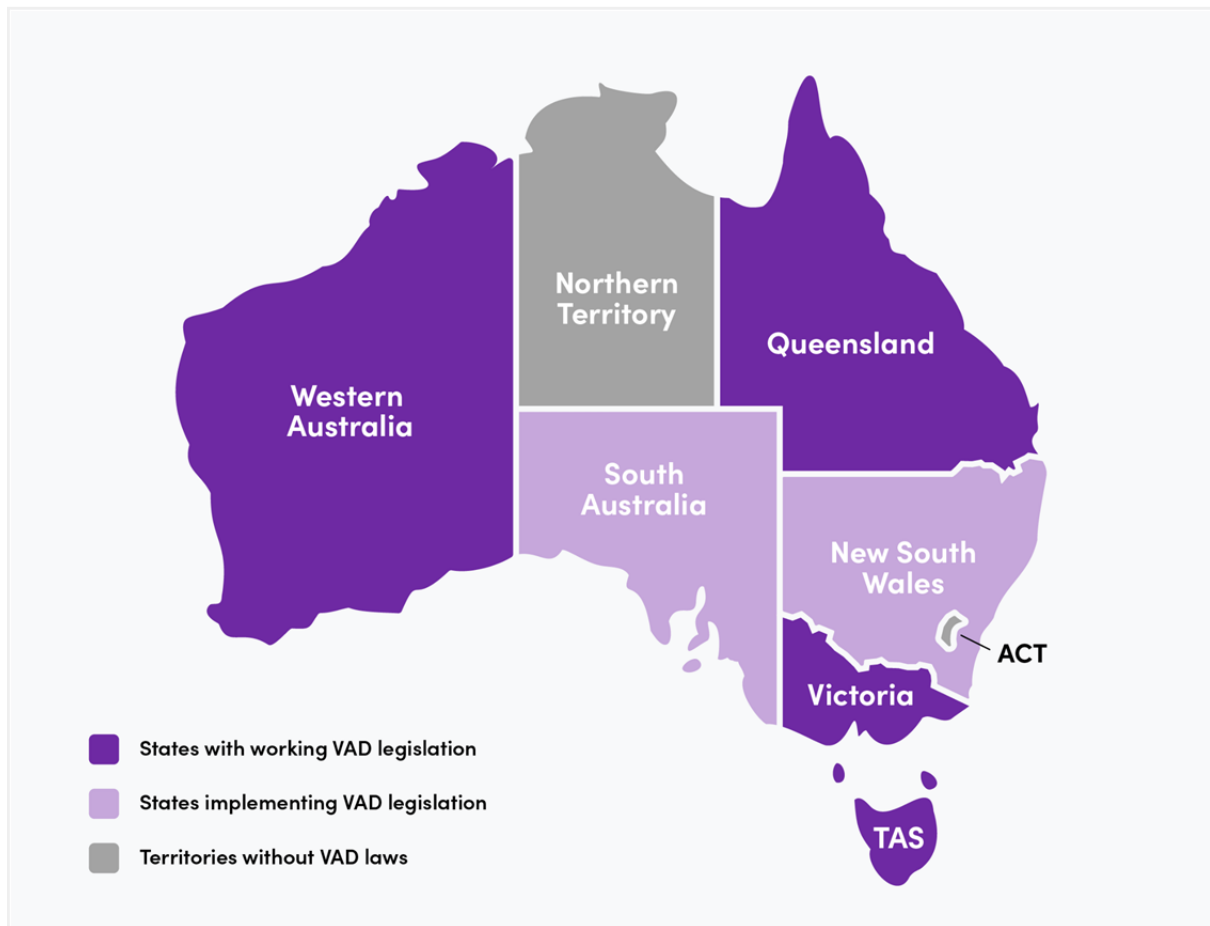
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Introduction

Go Gentle Australia is a national charity established in 2016 to promote choice at the end of life. We empower people to choose the end-of-life care that is right for them, including the option of voluntary assisted dying (VAD). We have played a critical role in the introduction of VAD legislation in Australia, where all six states have now passed laws. We believe the voices of dying people should be heard and their decisions respected.

This submission will focus on the second term of reference: **What can be learnt from the evidence in countries where assisted dying is legal?**

Voluntary Assisted Dying in Australia



Australia's embrace of VAD began in 2017 when Victoria became the first state to pass a law. It was described as "the most conservative law of its kind in the world."¹

Since then, all state parliaments have passed their own legislation; Western Australia in 2019, Tasmania, South Australia and Queensland in 2021 and New South Wales in 2022.

Each state's law came about after significant levels of public consultation. Each built on the strengths (and addresses the weaknesses) of laws that came before. The result is similar, but not uniform, legislation across the country.

All the laws have had at least 18-month implementation periods before they take effect, to establish processes and train healthcare professionals. Victoria, Western Australia, Tasmania and Queensland's laws are all currently effective.

By the end of 2023, all state laws will be operating (South Australia's law commences operation on 31 January and the NSW law will begin on 23 November). This means all Australians, bar the 700,000

¹ 'Assisted dying law a credit to Victoria's Parliament; now for federal change' 29 Nov 2017, The Age <https://www.theage.com.au/national/victoria/assisted-dying-law-a-credit-to-victorias-parliament-now-for-federal-change-20171129-gzvct2.html>

people in the Northern Territory and Australian Capital Territory (ACT), will be able to access VAD if they become terminally ill (and they meet strict eligibility criteria).

The ACT government has begun public consultation with the aim of introducing legislation in mid 2023.²

The Australian model

Although each state's law differs slightly, all Australian VAD legislation follows a similar framework, which has become known as the 'Australian model' of VAD. This limits medical assistance to die to terminally ill adults of sound mind who are suffering intolerably.

Broadly, to use VAD in Australia a person must be:

- **Diagnosed with an incurable disease, illness or medical condition** that
 - is advanced, progressive and will cause death within 6-12 months (depending on the nature of a person's disease)
 - is causing suffering that cannot be relieved in a manner the person finds tolerable
- **Capable of making decisions** about their medical treatment and communicate those decisions throughout the assessment process
- **Acting freely and without coercion**
- **Aged 18+**
- **An Australian citizen or permanent resident** who has lived in their chosen state for at least 12 months
- **Request VAD** at least three times
- **Be assessed and approved** by at least two doctors

Disability, mental illness and advanced age alone do not meet the above criteria; to access VAD in Australia, a person must also be terminally ill.

There is a rigorous request and assessment process and the process can be stopped at any time - by the individual, or by a VAD practitioner if any duress or coercion is suspected.

The diagram below summarises the process, as designed by ELDAC³:

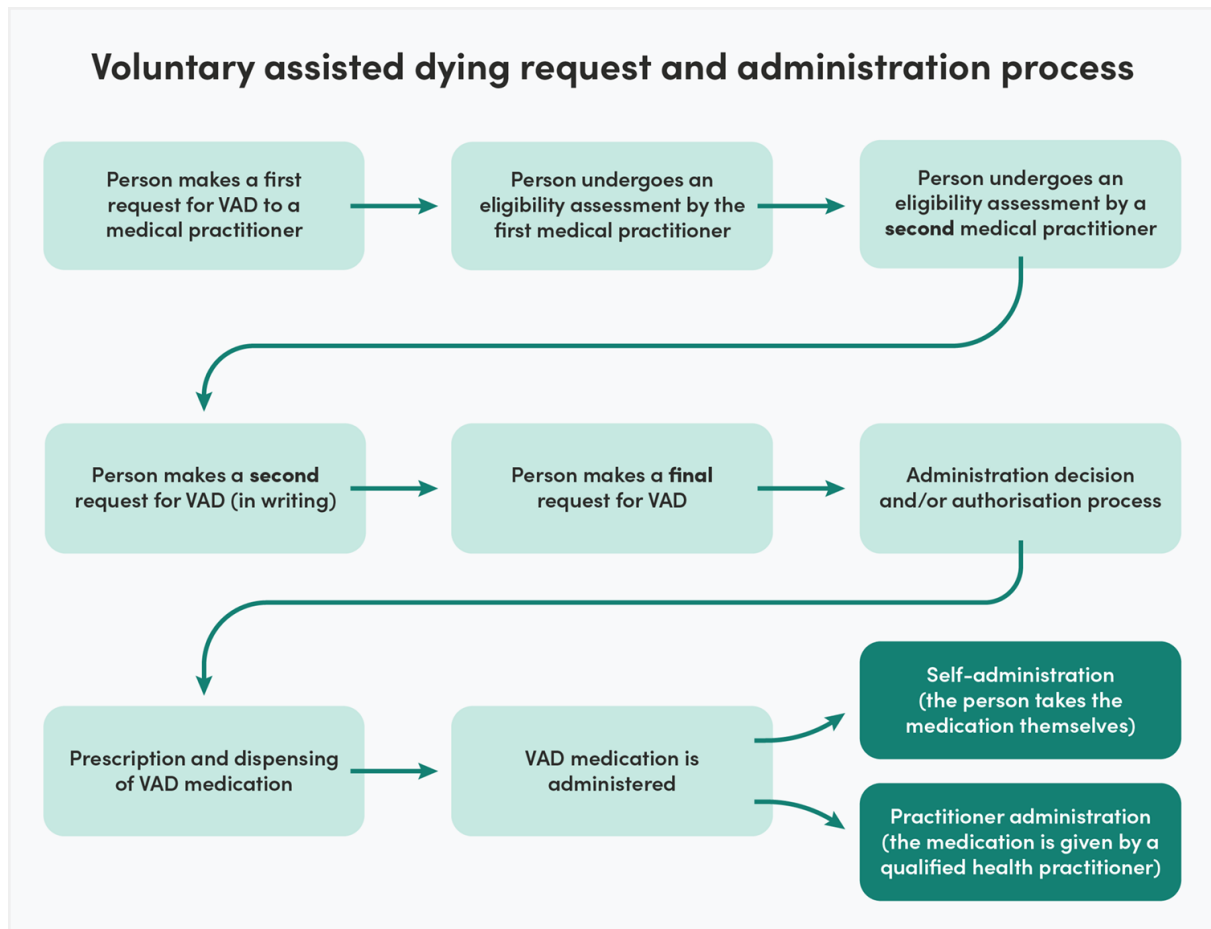
² 'Andrew Barr says ACT to introduce voluntary assisted dying laws in 2023' 1 Dec 2022, Canberra Times

<https://www.canberratimes.com.au/story/8002335/barr-outlines-path-to-acts-voluntary-assisted-dying-laws/>

³ End of Life Directions for Aged Care

https://www.eldac.com.au/Portals/12/Documents/Factsheet/Legal/Toolkit-Voluntary-assisted-dying_v11_2022.pdf Accessed Jan 2023.

Voluntary assisted dying request and administration process



What we've learnt from Victoria and Western Australia

Victoria's law has been in operation since June 2019, providing more than three years of robust evidence of how VAD works in an Australian context. Crucially, the Victorian experience makes it possible to examine the concerns raised about VAD (for example, vulnerable people would be killed, or that palliative care would be damaged) and determine whether they have turned out to be true.

Victoria's Voluntary Assisted Dying Review Board, the statutory body tasked with monitoring the law, have published biannual reports⁴ containing data and feedback from those who have chosen to use the law, and those who were with them when they died, including family, friends, doctors and carers.

The reports show that the Victorian legislation is operating safely and as intended. Terminally ill people are being helped to die under the circumstances of their choosing with a deep level of compassion, integrity and care. **They also make clear that none of the dark predictions about VAD have come to pass.** The law is operating within the strict eligibility criteria and safeguards determined by parliament, with a compliance rate close to 100%.

⁴ Victorian Assisted Dying Review Board reports available here: <https://www.safercare.vic.gov.au/publications?f%5B0%5D=agency%3A751&search=voluntary%20assisted%20dying%20review%20board>

Assisted deaths in Victoria account for a tiny proportion of total deaths each year – less than 0.5%. There have been no ‘wrongful’ deaths referred to police, no rogue doctors abusing the system and no evidence of coercion of the vulnerable.

Feedback from Western Australia⁵, where a similar VAD scheme has been operating for 18 months, mirrors the positive Victorian experience. In its first annual report, the independent Review Board noted that the Voluntary Assisted Dying Act is working well and that “medical practitioners, care navigators and pharmacists have given beyond the normal call of duty to provide comprehensive end of life care to those Western Australians who have made [this] choice”. The WA Board noted that demand for VAD had been greater than in Victoria, with VAD deaths representing 1.1% of all deaths in the time period. The Board’s recommendations centred on ensuring equity of access for people in rural areas by increasing the number of trained VAD practitioners and ensuring doctors are properly remunerated for the hours - and often significant travel time - they put into VAD assessments.

Laws in Tasmania and Queensland have been effective for less than six months and as such there has been no release of official data. However, given the similarities of the laws, their performance is expected to mirror the positive experiences in other states.

Why legislate for VAD?

Key points

Palliative care works for most - but not all

While palliative care is excellent and accommodates the needs of the majority of dying people, even the best-resourced care cannot relieve the extreme suffering some people endure. Palliative Care Australia acknowledges this:

*While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal care.*⁶

It’s not about pain, it’s about suffering

Pain isn’t the only suffering experienced at the end of life. Depending on your condition, there can also be bone metastases, distention, open sores, weight loss, odour, disfigurement, incontinence, fatigue, disfigurement, a sense of suffocation, continuous bleeding and paralysis. It is hard to imagine why a modern health system would abandon patients to these horrors when there exists a means to relieve them.

Palliative care and assisted dying work together

⁵ Western Australia Voluntary Assisted Dying Reports available here:

https://ww2.health.wa.gov.au/Articles/U_Z/Voluntary-Assisted-Dying-Board

⁶ Palliative Care Australia, ‘Policy Statement on voluntary euthanasia’, Canberra , 2006, p.2

Quoted by Neil Francis, Dying For Choice, ‘AMA Uncovered: How its own review exposed its assisted dying policy as indefensible’ p. 20

<https://www.dyingforchoice.com/docs/AMAUncoveredFullReport27Mar2017.pdf>

It is not a choice between palliative care OR assisted dying. The two can, and do, coexist. Evidence from Victoria and WA shows around 80-85% of people who choose VAD are also receiving excellent palliative care. VAD is simply another option.

Moreover, the existence of VAD laws does not result in a decline in palliative care. In fact the opposite is true. A 2018 report commissioned by Palliative Care Australia, looking at the impact of VAD on palliative care internationally, found:

“There is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards... if anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.”⁷

The Australian experience reinforces this. Since the first VAD law was passed in Victoria in 2017, more than \$1 billion in extra funding has gone to palliative care across Australia, including a \$743 million boost in NSW, the last state to pass a law.

Australians’ experiences of VAD

Families of those who have used VAD laws in Victoria and Western Australia have described the peace of mind and relief that having choice and control gives to dying loved ones.

The words they most commonly use to describe these VAD deaths are “peaceful”, “dignified” and “perfect.”

The extent to which the laws are working safely and compassionately is revealed by the case studies of the first people to use VAD in each state.

The stories of Kerry Robertson & Mary Ellen Passmore

‘She left this world with courage and grace’

Kerry Robertson was the first person to use Victoria’s VAD law. The following account was written after an extensive interview with her daughters.⁸ A version can also be read in *The Age*.⁹

⁷ Aspex Consulting, ‘Experience internationally of the legislation of assisted dying on the palliative care sector – Final Report, Palliative Care Australia, October 2018
https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

⁸ Interview with Nicole Robertson and Jacqui Hicks, Go Gentle Australia, 29 July 2019
https://www.gogentleaustralia.org.au/the_first_to_use_voluntary_assisted_dying_law

⁹ Melissa Cunningham ‘She left with courage and grace’: Daughters farewell Victoria’s first person to access assisted dying’ *The Age* Aug 4 2019
<https://www.theage.com.au/national/victoria/she-left-with-courage-and-grace-daughters-farewell-victoria-s-first-person-to-access-assisted-dying-20190802-p52d97.html>

Kerry Robertson, 61, died in a nursing home in Bendigo on 15 July (2019) of metastatic breast cancer.

Her daughters said: "It was a beautiful, positive experience. It was the empowered death that she wanted".

"We were there with her; her favourite music was playing in the background and she was surrounded by love," Jacqui said.

"That was the greatest part, knowing that we did everything we could to make her happy in life and comfortable in death," Nicole said.

Ms Robertson was diagnosed with breast cancer in 2010. Despite treatment, the cancer metastasized into her bones, lungs and brain. When the disease had also spread to her liver and the side effects from the chemo were no longer manageable, she made the decision to stop all treatment. Jacqui and Nicole said their mother had always known what she wanted.

"Mum already had an appointment booked to see her specialist the day the legislation came into effect, she made her first request that same day," Nicole said.

"Mum had always been brave, a real 'Feel the fear then do it anyway' mentality to life; it's the legacy she leaves with us."

The sisters said the assisted dying application process went smoothly and took 26 days. Ms Robertson took the medication on the same day it was dispensed by the statewide pharmacy.

"It was quick, she was ready to go. Her body was failing her and she was in incredible pain. She'd been in pain for a long time," Jacqui said. "Palliative care did its job as well as it could. But it had been a long battle. She was tired, the pain was intolerable and there was no quality of life left for her."

'Eternally thankful'

In July 2021, a 63-year-old Indigenous woman from Perth became the first identified Western Australian to use the state's Voluntary Assisted Dying law. Her story was told to Go Gentle Australia by her family¹⁰. It was also published in *The West Australian*¹¹ and *SBS Online*¹².

¹⁰ Interview with Mary Ellen Passmore's family, Go Gentle Australia, 30 July 2021
https://www.gogentleaustralia.org.au/indigenous_woman_among_first_to_use_western_australia_voluntary_assisted_dying

¹¹ Rangī Hirini, First known Aboriginal voluntary assisted dying (VAD) patient Mary-Ellen Passmore dies in Perth hospital, July 30 2021, *The West Australian* <https://thewest.com.au/news/health/first-known-aboriginal-voluntary-assisted-dying-vad-patient-mary-ellen-passmore-dies-in-perth-hospital-ng-b881946986z>

Mary-Ellen Passmore, a Wongatha-Yamatji woman, died in Perth on 29 July from motor neurone disease (MND). Her family described her death as “beautiful”.

“All were singing along to 'Hallelujah', including her doctors,” her sister said.

The family said Mrs Passmore had confirmed her choice multiple times before accepting the medication. She thanked her doctors and VAD coordinator and “gave them her love”.

Mrs Passmore had applied to be assessed for VAD soon after the law came into effect on 1 July and said she was profoundly grateful.

“I feel very honoured to choose when and where I can die,” Mrs Passmore said. “I am excited because I won’t have to suffer any more.”

Her family said: “We wish to express our gratitude that our proud Black mother, daughter, grandmother, sister, aunty, niece, cousin, godmother, friend, and mentor Mary-Ellen Passmore has been able to have her choice of a dignified death, voluntary assisted dying, finally fulfilled.

“We wish to thank the campaigners, the medical professionals, the families, and the state politicians who fought for the right thing - for the law to catch up and allow for choice and dignity.

Mrs Passmore had lived with MND, a degenerative neurological condition, for up to 12 years and received a formal diagnosis in 2015. In the past few months her pain had become unbearable.

She had become totally bedridden, had difficulty speaking and swallowing and was fed through a tube.

“It is terrifying being trapped by your own body and it’s a relief to know there will be an end to my suffering,” she said.

Medical perspectives

Voluntary assisted dying is increasingly accepted by the Australian medical community. In 2017, only two medical bodies openly supported VAD and 15 were opposed. By 2021, the number in support had risen to six, with 15 declaring a neutral position.

¹² Aaron Fernandes. ‘I’m at peace’: Aboriginal grandmother among first to use WA’s new voluntary assisted dying laws, July 30 2021, SBS. <https://www.sbs.com.au/nitv/article/2021/07/30/im-peace-aboriginal-grandmother-among-first-use-was-new-voluntary-assisted-dying>

How Australian medical bodies have changed their views on VAD

IN 2017 ONLY
TWO ORGANISATIONS
OPENLY SUPPORTED
VOLUNTARY ASSISTED DYING.
FIFTEEN
WERE OPPOSED

BY 2021
SIX ORGANISATIONS
SUPPORT VAD, AND
EIGHT ORGANISATIONS
ARE NEUTRAL

THREE ORGANISATIONS REMAIN AGAINST

IN 2021, most organisations are either neutral or in support of a Voluntary Assisted Dying law.



Only the three organisations below remain against.



Medical practitioners in Victoria and WA also describe the benefits of being involved in the assisted dying process.

Gentle and peaceful deaths

Dr Nick Carr, GP (VIC)

For the people who have gone through the process – and I have been there for a number of people who have taken the medication – it has been, it sounds odd really to describe dying as beautiful, but it has actually been a beautiful experience... It's been a positive experience for myself as a doctor.

Dr Simon Towler (WA)

I am amazed by how hard the VAD providers are working, driving and striving with little financial reward and putting significant pressure on their own families. In the end, the energy that drives the community of practice comes from the enormous privilege of looking after people who are showing all of us that facing your own death is an important part of living.

The patients have given so much more back and we have given to them. They are the heroes in the story and will continue to provide for them even if there are impediments. We respect, admire and applaud every VAD patient. It has been an absolute privilege to be part of the process.

Dr Clare Fellingham, Consultant Anaesthetist (WA)

Overwhelmingly, voluntary assisted dying deaths are peaceful, they're dignified, they're calm, they're gentle and compassionate, and they are truly, truly patient centred.

Personally, I found it an immense privilege to be involved so deeply and intimately in another person's life and experiences that I've gained and conversations that I've had with people. And what they've imparted in me has allowed me to cherish the time that I have, and appreciate my own life even more. I now choose to live more broadly, and actively look to seek out the joy in everything. And that is with an immense debt of gratitude to all the people who've shared all of their experiences with me.

Professionally rewarding

Dr Gareth Wahl, emergency physician (WA)

I had previously seen a very large number of unplanned deaths with things left unsaid and with both patient and family profoundly distressed and sometimes in pain. These [VAD] deaths are the complete opposite.

One patient chose to die with no one in the room except myself and my required witness. Mostly they've been surrounded by their closest family and on occasion, up to 30 of their closest friends. They've been surrounded by love. And most importantly, it's been how they've wanted. These people have died well. What I get back from this is really tremendously professionally satisfying. I walk away from this feeling that I've helped people. And that is something that my patients are giving me, that is worth much more than what I'm giving them. So yes, there is a cost, but there's a greater personal and professional gain.

Dr Peter Lange, geriatrician (VIC)

You're required to ask people the nature of their suffering, and I was a bit ashamed to see that my practice had unconsciously been to direct people to the suffering that I could relieve. So, I might have talked about suffering but the next immediate follow up question might have been how is your pain, how is nausea and those kinds of things which are more amenable to treatment. So, after starting to assess patients I realised that the nature of their suffering was often not those immediate symptoms but might well be a loss of purpose and dignity. I think it has changed my practice outside VAD.

Powerful palliative effect

Dr Philip Parente, oncologist (VIC)

Voluntary Assisted Dying is exceptionally patient-centred. We're allowing patients to take control when all the appropriate conditions are met in a very controlled way.

It's quite an amazing sight. They feel definitely more at ease, less anxiety, and they feel more in control. It doesn't necessarily mean they take it. Just having the option there gives them control and gives them hope.

Fiona Jane, Clinical Hospice Manager, Albany Community Hospice (WA)

In our experience of patients requesting VAD, we've seen improved patient-related symptom control of previously difficult to manage symptoms such as fatigue and anxiety. And this has happened almost as soon as the first assessment has been completed.

The process of VAD assessment acknowledges suffering caused by the burden of the disease process and the patient feels heard that their fear of increased disability, suffering and being a burden on their family is acknowledged.

Conclusion

VAD is working safely, as intended and with extraordinary integrity, care and compassion in Australia. It is increasingly recognised as a much-needed and powerful addition to end-of-life care. Given medical services and palliative care provision in Australia is comparable with the UK, we see no reason why UK patients cannot also benefit from this same end-of-life choice.

Jan 2023