



Conference Report

VAD CON 2023

27-28 September 2023

The inaugural trans-Tasman
Voluntary Assisted Dying Conference 2023.

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With thanks

We'd love to hear your feedback. Please email conference@gogentleaustralia.org.au to share anything we should think about for next year.

Foreword



G'day - and kia ora!

It's my pleasure to write the foreword to this report, marking the inaugural gathering of Australasian VAD providers and policymakers. It was a remarkable event for many reasons.

First, a conference to call our own - and so well and widely attended by practitioners, policymakers, peak bodies, politicians and health advocates alike. It showed how far we've come in embedding VAD in high-quality care provision in Australia and New Zealand. Thank you to all our esteemed speakers and attendees.

Second, we saw the launch of VADANZ, the new peak body for VAD health professionals and providers, which Go Gentle is proud to support. VADANZ will be a means of advice and support for VAD providers, by VAD providers. Most importantly, it will represent your expert, powerful and united voice, putting in place the right systems and supports to make sure VAD works well.

Third, we asked all delegates to vote on their top priorities for VAD reform. By far, the most pressing issue was changing the Commonwealth Criminal Code so that telehealth can be used for VAD. Legally, this is relatively easy - but getting it prioritised is more difficult. Rest assured Go Gentle and VADANZ are committed to raising the issue and hope to report success at the next conference.

Finally, I want to extend sincere thanks from all at Go Gentle Australia. We would not be where we are today without your participation, interest and support.

I look forward to continuing to work together to ensure VAD is a safe, accessible and respected choice for years to come.

Linda

Dr Linda Swan
CEO, Go Gentle Australia



Acknowledgements

VADANZ Steering Committee

Dr Cam McLaren
Dr Gavin Pattullo
Dr Gareth Wahl
Susan Jury
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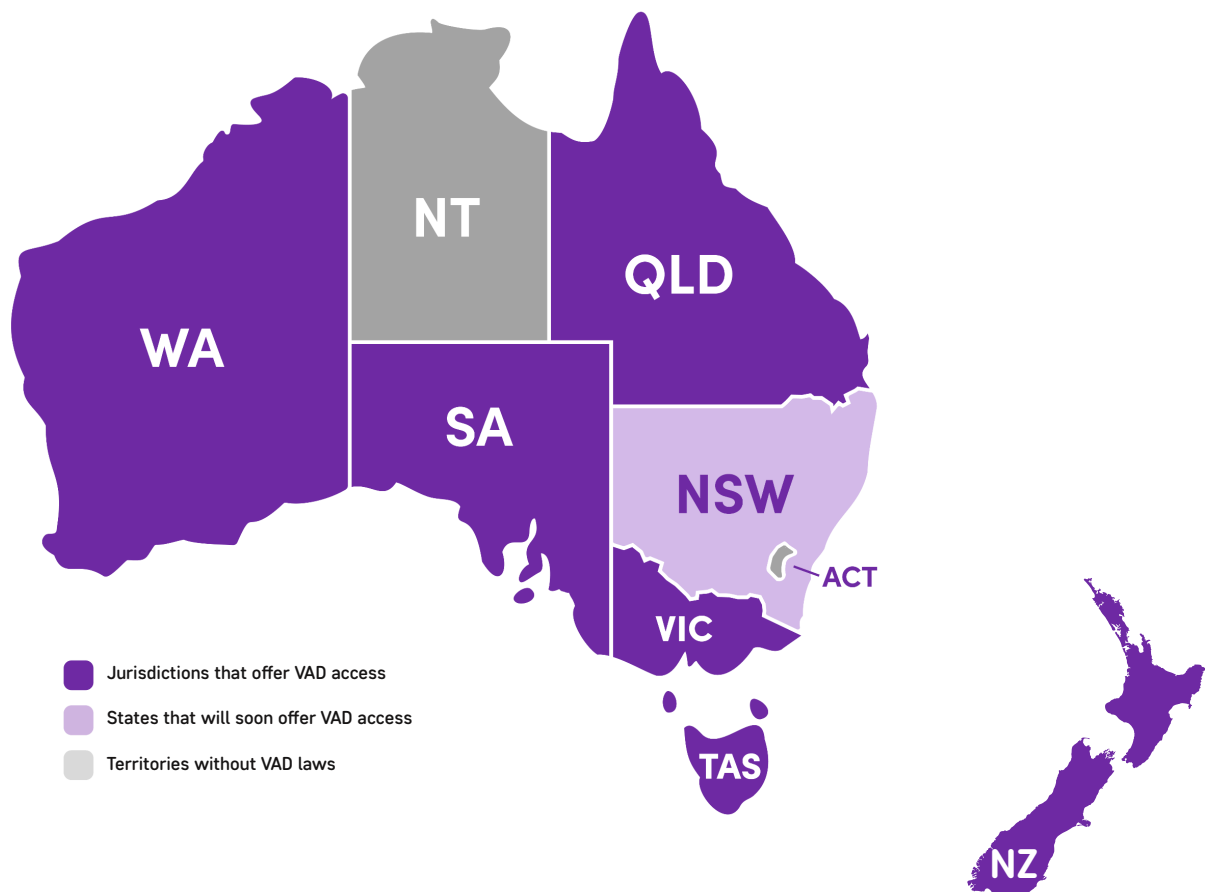
Conference Advisory Panel

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Professor Lindy Willmott
Dr Roger Hunt
Professor Ben White

Go Gentle team

Dr Linda Swan
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Gen Mater

VAD in Australia and New Zealand



Overview

The inaugural trans-Tasman VAD Conference was a welcome and timely addition to the calendar, bringing together 400 multidisciplinary health care professionals and policymakers to discuss how this growing area of clinical practice can best meet the needs of the community it serves, continue to deliver high-quality care and secure its sustainability in the long term.

The first day of the conference opened with the launch of VADANZ, the peak body for VAD professionals. Professor Ben White then led a panel with members of each jurisdiction's independent VAD Review Board about their respective laws before delegates broke into groups to identify 'pain points' for both clinicians and their patients. We discussed areas for improvement and the sustainability of VAD services, before delegates voted on the most pressing issues for VAD in 2024.

The second day welcomed policymakers, peak bodies and health advocacy organisations to join clinicians to hear frontline insights and develop priorities. South Australian Attorney General Kyam Maher delivered an opening address while Dr Paul Eleftheriou chaired a session on the experience of participating and non-participating providers. We heard moving personal accounts from people intimately involved in VAD and specialists in palliative medicine discussed how to incorporate VAD as part of usual practice before focus turned to the sustainability of VAD and how best to develop and support clinicians. The conference closed with a presentation on the future direction of VAD in Australia and New Zealand.

For the full program, click [here](#).



Policy priorities

Delegates voted for their top priorities for VAD reform. The top two priorities were:

- Allow telehealth to be used for VAD assessments
- Remunerate health practitioners for time spent on VAD care

These policy priorities will inform Go Gentle and VADANZ's advocacy and policy priorities, and we will provide an update on progress at the next conference.

Conference Snapshot



2 days in Sydney



400 delegates from across Australia and New Zealand



51 high-profile speakers



Launch of VADANZ - the peak body for VAD health professionals



First Australia-wide VAD survey to be repeated annually



Top priorities identified by delegates: reform of telehealth and remuneration



92% very or extremely likely to recommend the conference to colleagues

Highlights

Opening address from Kyam Maher MLC

SA Attorney-General and Minister for Aboriginal Affairs acknowledged the path to VAD legislation and reiterated his support for telehealth reform.

Personal reflections by Pauline McGrath and Sandi Olney

Pauline, whose husband used VAD in Queensland in early 2023, gave a moving talk where she reminded the conference of the difference VAD makes to individuals and their loved ones. Sandi's story, as a practitioner, demonstrated the unique bonds that can develop between practitioners and individuals on the VAD journey.

VAD Review Boards came together for the first time

A fascinating comparative panel of representatives from every jurisdiction's VAD Board or Commission and chaired by Professor Ben White, QUT, explored the differences between the laws and their operations.

New peak body launched

VADANZ, the peak body for health professionals and others working in assisted dying, was launched by directors Dr Cam McLaren and Susan Jury. Find out more at vadanz.org.au

First organ donation following VAD

Victoria's DonateLife team shared their pioneering experience fulfilling a VAD recipient's wishes to donate her organs.

Australia-wide VAD survey released

This new annual survey from Go Gentle, VADANZ and Nous compares VAD in different states to identify areas for improvement. It will build a longitudinal evidence base, with results published in a new yearly report. Take the 10-minute survey [here](#).

Updates from the Territories

The Australian Capital Territory's Minister for Human Rights, Tara Cheyne MLA, confirmed a VAD bill will be introduced this year. Co-Chair of the Northern Territory's VAD Expert Panel, Vicki O'Halloran AO CVO, outlined the progress of community consultations ahead of a VAD report due by July 2024.

Power of Choice exhibition

Award-winning photographer Julian Kingma gave a first look at the ongoing Power of Choice project that documents the VAD journeys of individuals and their carers, supported by Go Gentle.



Key themes

Success of the trans-Tasman VAD model

Representatives from every jurisdiction's independent VAD Review Board confirmed existing laws are working safely and as intended. Although there are minor jurisdictional differences, the broad assisted dying model adopted across Australia and New Zealand limits access to adults with a terminal illness and decision-making capacity who are suffering intolerably and have between 6-12 months left to live, as assessed by two independent doctors.

Commitment to person-centred care

VAD naturally centres on the dying person's needs and choices. However, a point of importance was ensuring the provision of a culturally safe and responsive VAD service for First Nations and Māori people, as well as people from culturally and linguistically diverse (CALD) backgrounds.

Improved collaboration between specialist palliative care and VAD

An overwhelming majority of the conference agreed that specialist palliative care and VAD work best together, especially as many VAD patients receive both. It was felt VAD should also be integrated with wider advance care planning and in medical education.

Better awareness and understanding of VAD for the public and clinicians

Ongoing investment is needed to increase the public's knowledge and understanding of VAD, as well as the need to include VAD in health curriculums to educate and train the next generation.

Provision of tailored grief and bereavement support

Specialist VAD support is needed in some cases as stigma can be encountered through mainstream channels. Some families have reported that grief following VAD can feel distinct.

Harmonisation of Australian VAD laws

In Australia, laws differ slightly between states. The conference agreed harmonisation of these laws would improve continuity of care and clarity, aiding better operation and outcomes for clinicians and patients.

Issues

Safeguards or barriers to access?

It was widely agreed that the following issues did not contribute to patient safety, but instead acted as barriers to access for many people seeking VAD. The main barriers discussed were:

Prohibition on use of telehealth for VAD (Australia)

Ambiguity in the Criminal Code Act 1995 (Cth) prohibits telehealth from being used in the VAD process. This is a barrier to access for people seeking VAD who are too unwell to travel to in-person appointments or who live in remote areas. Health professionals often need to travel long distances to patients, and this can add delay, stress and complication to an already complex VAD process.

Prognostication and timeframes

The requirement in the majority of jurisdictions that a dying person must have less than six months to live to access VAD (or 12 months for neurological conditions) was considered an impediment to care resulting in some people leaving it too late to complete the assessment process. Tasmania's optional exemption was widely endorsed by the conference, as was support for Queensland's universal 12-month timeframe. Conference delegates agreed that standardisation of timeframes across jurisdictions and simplifying the processes for eligible people needs further discussion.

Gag clause (Victoria, South Australia and New Zealand)

The so-called 'gag clause', which prevents doctors from raising VAD with their patients, was raised as a troubling barrier to people's right to know the full range of care and treatment options available if they are diagnosed with a terminal illness.

Residency requirements (Australia)

With VAD laws effective in all Australian states from November 2023, state-based residency requirements are an unnecessary hurdle and barrier to access – particularly for people moving interstate to access care or to be closer to loved ones.

Low VAD participation in aged and hospice care

Many residential aged care and hospice providers do not participate in VAD. Some VAD laws impose obligations to facilitate access to VAD, either by transfer to another provider if that would not cause the person harm or, in the case of permanent residents of aged care, external VAD practitioners to be allowed on-site. Several VAD laws (Victoria, WA and Tasmania) are silent on the matter.

Either way, some patients face additional barriers to accessing VAD due to the non-participation of their care provider – especially if they do not have the option to move to another facility. Many delegates stated publicly funded health services should not be allowed to obstruct a person's access to VAD information, assessment or administration.

A faith-based VAD provider proposed that a possible solution was to provide guidance to help develop policies and procedures to accommodate choice. It was often not a lack of will, but a lack of understanding, that slowed the acceptance of VAD into standard practice and care delivery.

Ensuring sustainability of VAD

The conference widely acknowledged that VAD works because dedicated health professionals go above and beyond. However, further thought is needed to ensure the system is sustainable:

Recruitment of VAD practitioners

Given VAD is a new area of practice, the majority of cases fall on the shoulders of relatively few practitioners. Accepting a high volume of VAD cases, often in addition to existing workloads, risks burnout; particularly as VAD can involve short timeframes and travelling to a person's home. One suggestion strongly approved by the conference is to enhance the role of nurses in the VAD process.

Remunerate health professionals for time spent on VAD care (Australia)

In Australia, VAD is only partially covered by Medicare, with the MBS general explanatory notes (GN.13.33) explicitly ruling out "euthanasia and any service directly related to the procedure" from attracting Medicare benefits. This means GPs, who take the majority of cases in Australia, are often working unpaid. While many practitioners said they find VAD deeply rewarding, they also said the current model is unsustainable.

New Zealand's funding model was suggested as best practice. There the VAD process is broken down into five main modules, each with a fixed price payment based on an estimate of the number of hours involved for the services. Additional payments can be made available for extra duties such as obtaining clinical notes, travel allowance, complex cases and supporting other practitioners.

Also discussed was the 'VMO Model' soon to be rolled out in New South Wales. This will see VAD-specific roles created and employed by NSW Health and based at Royal North Shore Hospital and in designated regional centres. VMOs (Visiting Medical Officers) will be funded to travel to provide VAD, with the expectation that this will lighten the burden of travel on other VAD providers.



Delegates told us...

We asked Day 1 delegates to identify the pain points in the VAD process for practitioners and patients.

Pain points for patients included

- A lack of public awareness that VAD is an option, exacerbated by the 'gag clause' in Victoria, South Australia and New Zealand which prevents health professionals from raising VAD with patients
- A struggle to navigate the VAD process; finding accurate information, VAD-trained health professionals in their area, and preparing paperwork
- Access challenges, particularly for people living in aged care, prison, who are homeless or who come from culturally and linguistically diverse backgrounds.

Pain points for practitioners included

- Too few VAD practitioners, resulting in high workload and burnout
- Inadequate funding and unpaid work, risking VAD's sustainability
- An overly bureaucratic system.

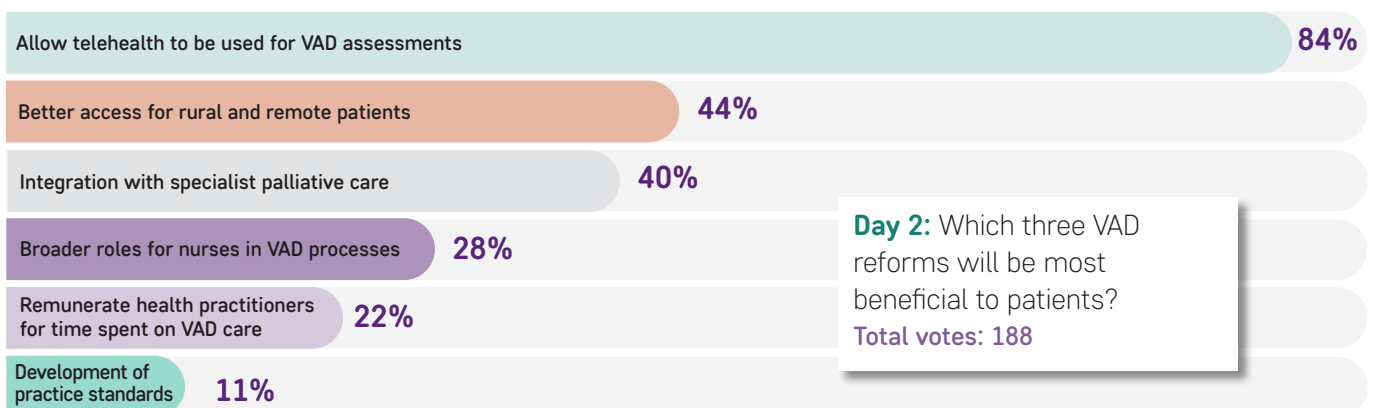
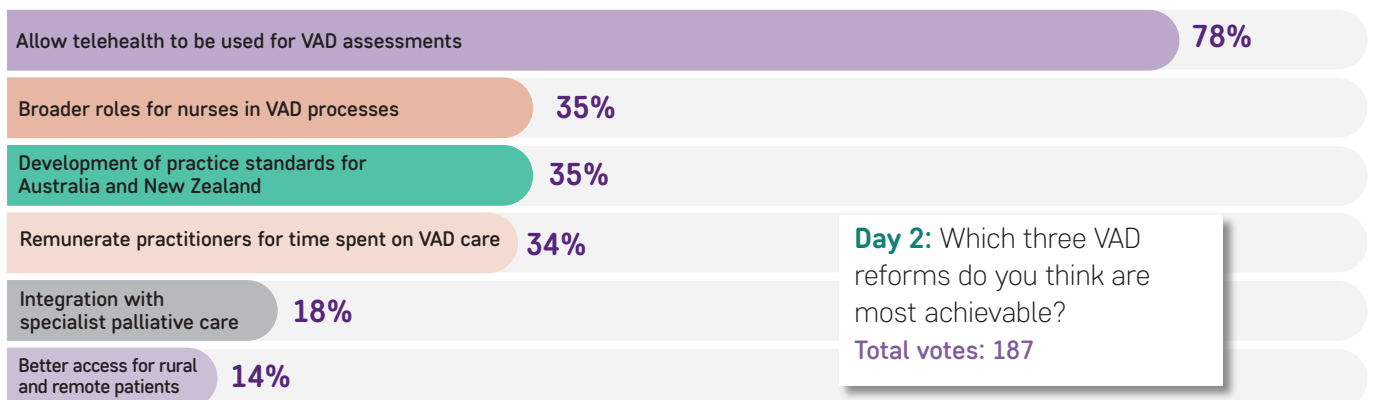
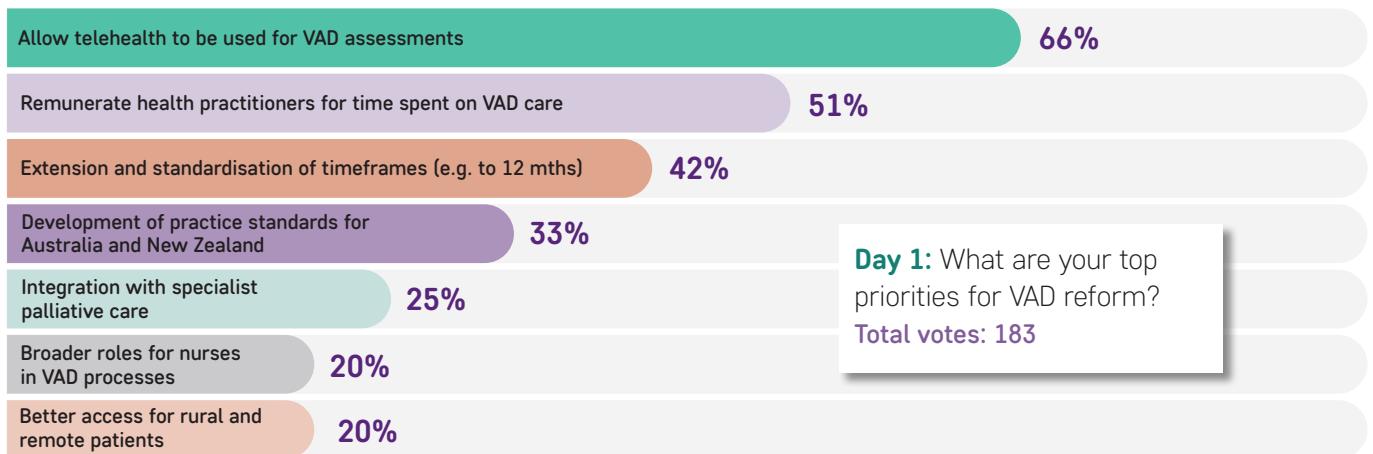
Pain points affecting both groups included

- Telehealth restrictions, causing delays and complicating the VAD process
- Obstruction from individual practitioners and institutions
- Perceived or real stigma associated with providing or accessing VAD.



Delegates voted...

We asked delegates to vote for the most pressing VAD reforms in 2024, so we could align our top priorities and shape collaboration. The results are below.



Top two policy priorities overall

- Allow telehealth to be used for VAD assessments
- Remunerate health practitioners for time spent on VAD care



VADANZ was launched at the conference as the new peak representative body for health professionals providing VAD in Australia and New Zealand, as well as those working in operational and administrative VAD roles.

What do you want the peak body to do for you?

Be truly multidisciplinary

VADANZ's agenda and leadership will represent its multidisciplinary membership.

Provide a clinically experienced, evidence-based voice

VADANZ will champion the voice of VAD health professionals and draw on collective expertise to influence improvements to VAD care. Special interest groups will be developed.

Develop VAD Standards of Care

VAD is highly regulated but sits outside clinical standards. A key focus for VADANZ will be to develop VAD-specific Standards of Care (as already exist for end-of-life and palliative care).

Connect VAD health professionals

Working in VAD can be isolating. VADANZ will facilitate spaces where health professionals can speak to others working in similar roles and build a sense of camaraderie. The option of mentorship for new practitioners was raised.

Forums for discussion and sharing policy, practice and procedure

VADANZ will provide spaces where knowledge and best practice can be shared.

Define VAD as a profession

VADANZ will support VAD as a distinct profession and develop education materials beyond the mandatory training, such as advocating for VAD in health curriculums.

Develop standardised data points

VADANZ will work towards standardised data collection across Australia and New Zealand, to aid comparison and improve evidence.

Create and inform a research agenda

VADANZ will foster partnerships with QUT, Victoria University of Wellington and others, to support evidence-based development of VAD operation and practice.



Want to get more involved in VADANZ?

Do you have ideas you'd like VADANZ to work on? Are you interested in a leadership position or starting a special interest group?

Contact the VADANZ team at admin@vadanzenz.com.au

VAD national survey

Go Gentle has partnered with VADANZ and Nous to deliver the National Voluntary Assisted Dying (VAD) Survey, the first and most comprehensive of its kind in Australia. The survey asks those involved in VAD, from people with terminal illnesses and their families to clinicians and policy experts, what's working well and what could be improved.

The data will be used to assess how the operation of VAD differs between states and identify areas of improvement.

The survey will be repeated regularly to track changes, identify trends and build the evidence base of VAD practice in Australia, with results to be published in an annual report.

Please complete the survey and share the link with your colleagues:

www.vadsurvey.com.au

The next conference: VADCON24

The location and dates for the next conference will be communicated as soon as possible.

You told us that next year's conference should have a strong research focus, examining new ideas and innovation in VAD. As such, we're excited to announce that VADANZ and Go Gentle will work closely with the Australian Centre for Health Law Research at QUT to develop a research agenda. We will invite abstracts, and keep you updated about the submissions process.

With thanks

To our speakers and presenters

Molly Carlile AM
Tara Cheyne MLA
Dr Paul Eleftheriou
Josh Fear
Dr Clare Fellingham
Julian Gardner AM
Dr Kristin Good
Dr Hannah Gould
Nick Hobbs
Suzie Hooper
Helen Irving
Julian Kingma
Tiny McCafferty
Pauline McGrath
Haley McNamara
Dr Greg Mewett
Louise Mollross
Dr Anna Negus
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Sandi Olney
Tsultrim Pearse
Jane Pickering
Meg Plaster
Hayley Russell
Linda Savage AM
Dr Wade Stedman
Nicky Stitt
A/Professor Melanie Turner
Larna Woodyatt

And all the volunteers, without whose support the conference would not have been possible.





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