



Annual Report

2020

Voluntary Assisted Dying:
An issue whose time has come

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SPARKING A BETTER CONVERSATION
AROUND END OF LIFE.





Contents

06

A Message from Andrew Denton

14

2020 Highlights

07

A Message from the CEO

16

Voluntary Assisted Dying:
An issue whose time has come

08

Who We Are

18

Awareness and Health Promotion

10

Our Team

20

Research and Advice

11

Our Board

22

Education

12

2020 Achievements

24

Operations

A Message from Andrew Denton



End-of-life choice is not, as some would paint it, a fringe social issue. It speaks to a core responsibility of any caring society: how we treat our most vulnerable, the terminally ill.

Even five years ago, most politicians considered laws offering people the choice of assisted dying as 'a step too far', despite repeated opinion polls showing community support between 70 and 80%.

Influenced by a powerful coalition of Church leaders and doctors with shared values, for decades parliaments across Australia voted against change. By the end of 2016, 50 attempts to pass VAD laws had been defeated.

And then, in 2017, everything changed. Victoria became the first Australian state to pass a voluntary assisted dying law. Two years later, Western Australia followed suit.

By the middle of 2020, this landmark law reached a significant milestone – a full year of operation in Victoria. With the anniversary, it became possible to look at the issues raised in the parliamentary

debate to see whether or not the fears expressed at the time have turned out to be true.

Seeking to cast light on how the law was working, I spent the second half of 2020 speaking with those most intimately involved in it.

As well as families of those who used the law, I interviewed GPs and specialists; palliative care physicians; pharmacists who deliver the medication; care navigators who guide people through the law's many steps; and those responsible for making sure it is operating as it should.

These are being assembled into a second season of the podcast *Better Off Dead*, which will be released in March 2021. We are hopeful these stories will play their part in persuading other Australian parliaments to follow the lead of Victoria and Western Australia.

What struck me as I dived into the first year of Victoria's law was the deep level of integrity and care with which everyone involved approached the needs of the terminally ill. The profound humanity on display, most of all from families, was only surpassed by the courage of those who made the choice not to suffer any longer.

What was also clear is that none of the dark predictions made about assisted dying in the parliamentary debate turned out to be accurate.

The largely positive Victorian experience is already having a wider impact. Citing its example, Tasmania's parliament embarked on a sophisticated debate in 2020, and looks set to become the third state to pass such a law. South Australia,

Queensland and NSW, too, have indicated they will debate similar bills in 2021.

2020 also brought unexpected recognition for our cause: Three advocates of VAD laws – myself included – were named as finalists in our respective state Australian of the Year Awards. Even a few years ago such acknowledgement would have been unthinkable. It is those who oppose these laws who now, clearly, sit apart from the Australian mainstream.

While we are buoyed by this momentum for change, there is still much to do. Despite the flurry of new bills, the 'rightness' of a cause is no guarantee of its success. The reality is two-thirds of Australians still have no access to voluntary assisted dying laws. And – as ongoing efforts to discredit Victoria's law have demonstrated – reforms that have been hard won must be vigorously defended.

The progress described in these pages is the result of years of persuasion, education and dedication by countless groups and individuals. A heart felt thank you to everyone who has stood up for the terminally ill, and their right not to suffer at the end of life. Your commitment gives our cause something no politician or parliament can easily ignore – strength in numbers.

As we approach the year ahead, we do so inspired by nurse Margaret Radmore, one of the 124 people to use Victoria's law in its first year. Let the five simple words she uttered to explain her decision be those by which we march:

'I choose not to suffer'.

A Message from the CEO



Kiki Paul, CEO.

We started 2020 with great plans. We travelled to Melbourne in March to attend a conference of Dying With Dignity organisations in Australia. We compared notes about previous campaigns, shared information and caught up with friends.

Little did we know the world was about to change dramatically. Our ideas for research involving face-to-face workshops had to be put on ice as the world shut down around us.

Just like everyone else, we have had to adjust to a new way of working. We worked from home for a while and soon Zoom became our new best friend, one we've all come to know a little too well!

The silver lining was that we put on our first webinars for the annual Dying to Know Day. Both were very well attended and we will definitely continue them next year.

Many of our efforts this year were behind the scenes. We put together resources to support campaigns and updated existing documents, such as *A Guide to the Debate on Voluntary Assisted Dying*. As developments unfold, we continue to make changes to ensure these remain current.

The second half of the year saw us provide support to the Yes For Compassion campaign in New Zealand. The NZ parliament had already passed a VAD law but it needed to be endorsed by referendum at the time of the general election. Almost two-thirds (65.1%) of New Zealanders voted Yes, which means the VAD law will come into effect in November 2021.

In Tasmania, Michael Gaffney MLC worked tirelessly on his End of Life Choice (Voluntary Assisted Dying) Bill 2020. We worked closely with him to provide support and materials for his fellow MPs.

In the last part of the year, we focused on an exciting project; the second season of Andrew Denton's podcast *Better Off Dead*. The first season, launched in 2016, explored assisted dying legislation overseas and why we do not have similar laws here. It was the impetus to start Go Gentle Australia. The new season looks at how the law is operating in Victoria and will be available in early 2021.

While much of our focus is on legislation, we must also not forget the importance of end-of-life conversations. While in Victoria (and soon in WA) these can

include voluntary assisted dying, the conversations cover so much more. The pandemic has brought to the fore how important it is to know the end-of-life wishes of our loved ones. It is never too early to talk about these.

We close off 2020 with no fewer than four states in the process of considering voluntary assisted dying legislation: Tasmania is preparing to debate a bill in detail in the House of Assembly; in South Australia a draft bill has been tabled in both Houses; Queensland is preparing to consider a bill that is currently before the Law Reform Commission; and in NSW, Independent MP Alex Greenwich has announced his intention to draft and table a bill in the second half of the year.

Voluntary Assisted Dying is indeed an issue whose time has come.

Thank you to everyone who has supported our efforts this year – from donations, to telling your story and participating in our online events. Your generosity and enthusiasm is the reason why 2021 is shaping up as a watershed year for end-of-life choice in this country.

Who We Are

Our Mission

To spark a better national conversation around death and dying, and end-of-life choices.

Our Objective

To help relieve the distress, helplessness and suffering experienced by Australians with untreatable or terminal illnesses, and their families and carers.

To achieve this we:

- Provide education for a better conversation about death and dying and end of life options (within current legal frameworks).
- Act as a central point of connection for all voices supporting Voluntary Assisted Dying (VAD) and act as a representative of the community in educating and informing policy discussions on assisted dying approaches and best practices.
- Create a central hub of information for all matters related to end-of-life conversations and choices.

Strategies

- Create an ongoing national archive of testimonies from people living with a terminal illness, families, doctors and nurses
- Create an information bank about VAD laws and issues nationally and around the world
- Connect relevant medical, legal, political and community expertise around Australia
- Develop and provide educational resources and tools to improve the national conversation around death and dying
- Continuously evaluate and correct misinformation about VAD.

Values

Go Gentle Australia is an organisation that values choice, respect, compassion and integrity.

CHOICE

We argue for the choice to decide what happens to us at the end of our lives, including not to be forced into avoidable suffering when we are at our most vulnerable.

RESPECT & COMPASSION

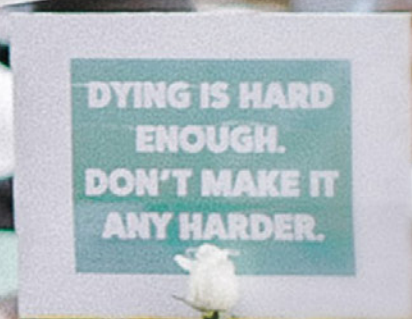
We respect the right of all Australians to hold differing religious, spiritual and secular beliefs. We treat everyone with respect and compassion.

INTEGRITY

We abide by strict standards of evidence gathering and only provide truthful information. We are open and honest about our positions and partnership, and always operate within the law.



Go Gentle Australia does not argue for a 'right to die'. We see death not as a right, but as a fact at the end of life. We are all in this together – we can help each other to go gently.



Our Team

Kiki Paul

CEO

After 20 years in financial services, Kiki has used her business experience in the not-for-profit sector. She has served on the board of the Hornsby Ku-ring-gai Women's Shelter. She joined Go Gentle Australia at its inception in 2016. She is passionate about social justice, equal opportunities and making the world a better place.

Steve Offner

COMMUNICATIONS MANAGER

Steve joined GGA after more than a decade in corporate communications and a stint as media adviser for the Australian Marriage Equality Campaign. He coordinates GGA's national communications strategy, media engagement, and GGA's digital and social media platforms. He holds a Master of International Relations from UNSW and a Bachelor of Communications/Journalism from Charles Sturt University.

Renae Titchmarsh

PROJECT OFFICER

Renae's skills as a graphic designer have made her an invaluable asset to the team. Renae is responsible for ensuring brand recognition and consistency across all GGA assets. She is passionate about accessibility, legibility and functionality when designing.

Our Board

GGA's board members are all volunteers who bring significant experience from their fields of expertise. The Board meets monthly to guide and assist the organisation to achieve its strategic goals.

Peter Thompson

Peter has extensive experience in commercial and corporate law, specialising in the entertainment and media industries.

Andrew Denton

Andrew is one of Australian media's genuinely creative forces with a career covering radio, television and film. He is the creator of the podcast series Better Off Dead, investigating why good people die bad deaths in Australia.

Tanya Jones

Tanya is a strategic communications professional with over 20 years of experience running large corporate, brand and political advertising campaigns.

Craig Stafford






Craig has worked in the finance industry for 25 years spending most of that time researching, and helping clients invest in, listed companies in Australia and throughout the world. He is passionate about health, education and sport. Craig is currently Associate Director of Research (ANZ) at UBS Securities Australia.

Brian Owler

Prof Brian Owler is a neurosurgeon who treats both cranial and spinal conditions of adults and children. He chaired the Expert Ministerial Advisory Panel on Voluntary Assisted Dying in Victoria and is a past president of the AMA.

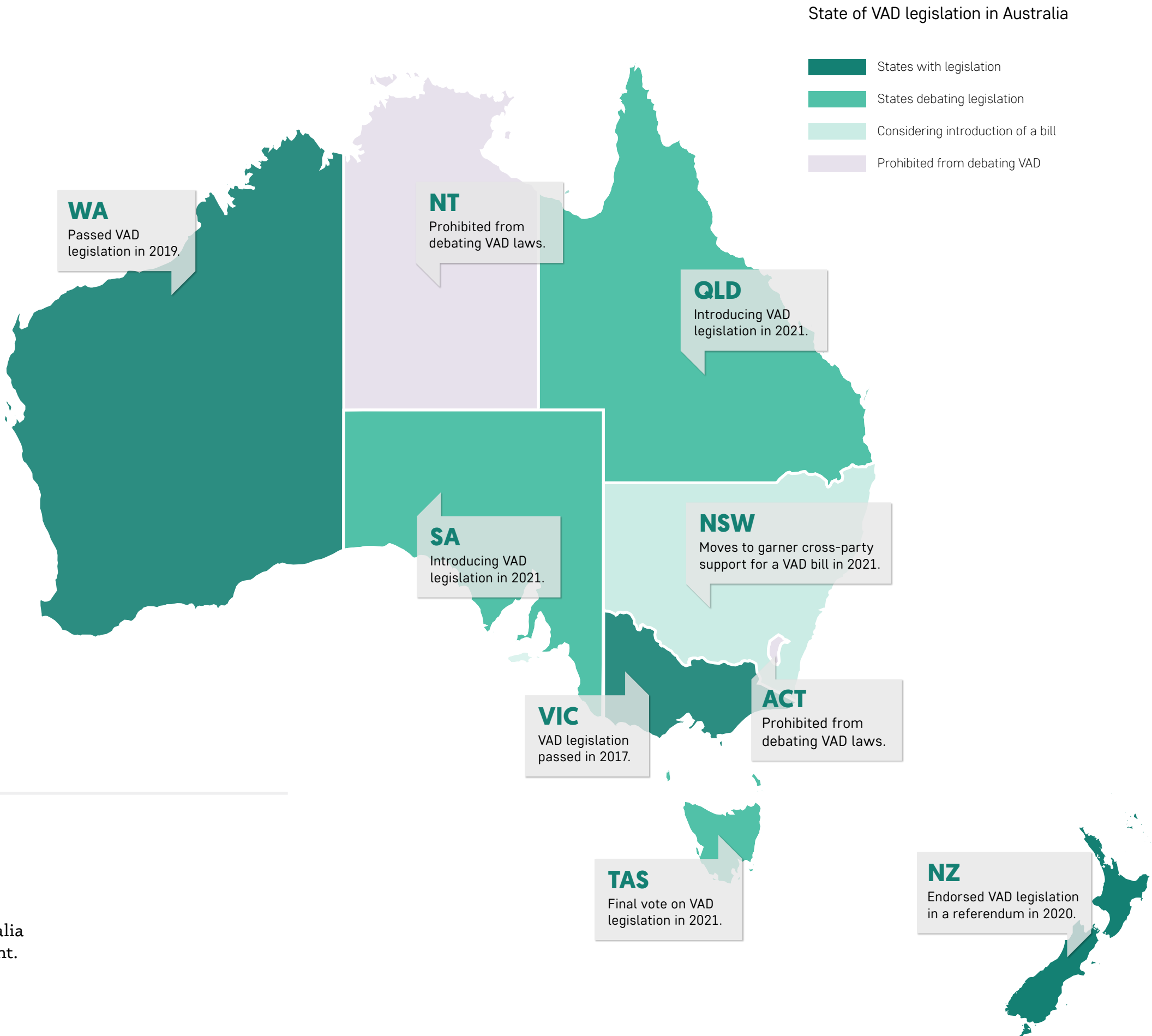


2020 Achievements

-  **17,857** supporters
-  **13.1K** Facebook followers
-  **549** donors
-  **3** advocates nominated for Australian of the Year awards
-  **4** states actively considering VAD laws

“It is absolutely essential that every Australian state, including the territories, has the law implemented to allow voluntary assisted dying. Every person in Australia is entitled to have the choice of this basic human right.”

Christine Jenkins, NSW supporter



2020 Highlights

21 JAN – GGA publishes 'Assisted Dying in Australia: Where to Next?' outlining the state of play of VAD legislation around the country.

12 FEB – MLC Mike Gaffney releases Tasmania's draft Voluntary Assisted Dying Bill for public consultation.

19 FEB – GGA welcomes the Voluntary Assisted Dying Review Board's second report, showing Victoria's VAD Act operating safely and as intended.

3 MARCH – SBS Insight airs episode on voluntary assisted dying, featuring VAD advocates.

20 MARCH – GGA temporarily closes office and works remotely in response to the Covid-19 pandemic.

31 MARCH – GGA welcomes a parliamentary inquiry report that recommends Queensland introduce a VAD law.

14 MAY – Western Australia's implementation panel says Covid-19 has not disrupted the VAD law's mid-2021 start date.

21 MAY – The Queensland government announces it will postpone debate on a voluntary assisted dying bill until 2021.

19 JUNE – Victoria marks the first anniversary of its VAD law, an important milestone for kinder, more compassionate end-of-life choices.

JULY 9 & 29 – GGA hosts inaugural Dying to Know Day webinars.

15 JULY – GGA shines a light on the undisclosed bias of a book about the upcoming NZ referendum on voluntary assisted dying.

19 AUG – Tasmanian Greens leader Cassy O'Connor tables in parliament a record 13,082 signatures in favour of legalising voluntary assisted dying.

1 SEPT – Independent MLC Mike Gaffney tables the End of Life Choice (Voluntary Assisted Dying Bill) 2020 in Tasmania's Upper House.

2 SEPT – GGA welcomes the VAD Review Board's first year review of the operation of Victoria's Voluntary Assisted Dying Act.

24 SEPT – GGA assists a Victorian family to respond to an online article that grossly misrepresents their mother's death through VAD.

13 OCT – South Australia's joint parliamentary inquiry into end-of-life choices stops short of recommending the introduction of a voluntary assisted dying law.

18 OCT – Queensland's Labor government promises to introduce a voluntary assisted dying bill if it wins the state election.

20 OCT – Victoria nominates veteran of the voluntary assisted dying movement, Dr Rodney Syme AM for 2021 Senior Australian of the Year.

30 OCT – The NZ electoral commission announces that 65% of voters in a referendum have endorsed the introduction of the End of Life Choice Act.

2 NOV – Andrew Denton, GGA's founding director, is nominated as a NSW finalist in the Australian of the Year awards.

6 NOV – Belinda Teh, the face of Western Australia's campaign for VAD, is a finalist for WA Young Australian of the Year.

10 NOV – Tasmania's End-of-Life Choice (Voluntary Assisted Dying) Bill 2020 passes the Upper House in Tasmania unopposed.

2 DEC – MPs Kyam Maher and Susan Close table a private member's bill in South Australia's parliament to legalise VAD.

3 DEC – The Tasmanian Lower House begins debate on the End-of-Life Choice Bill 2020.

4 DEC – The Tasmanian Lower House votes to send the End-of-Life Choice Bill to a third reading in 2021.

13 DEC – Independent MP Alex Greenwich announces intention to draft and table a VAD bill in the NSW parliament.

“

It is clear that, in its first year, the Victorian law is operating safely and effectively and is providing a welcome choice to terminally ill people at the end of life.

Kiki Paul



World First



Historic win for VAD in Tasmania

Tasmania's Upper House made history by becoming the first legislature in the world to pass a voluntary assisted dying bill unopposed.

The bill, introduced by Independent MP Mike Gaffney, won unanimous support in the Legislative Council in November after more than a year of public consultations.

In December, the Bill moved to the Lower House which voted 17-7 to send it to a third reading in 2021.

The extent of support across party lines suggests Tasmania is set to become the third Australian state to pass a voluntary assisted dying law. No previous Tasmanian VAD bill has made it so far.

The bill received support from the Premier Peter Gutwein and Deputy Premier Jeremy Rockliff (who had both voted against previous VAD bills) and from Health Minister Sarah Courtney, who agreed to take carriage of the Bill through the Lower House as the member for Bass.

The bill now becomes first order of business in the Lower House when Parliament resumes in March 2021.

That a non-government bill has progressed so far is testament to the work and skill of Mike Gaffney, who has drafted, tabled and championed the bill and to the grassroots public campaign led by Your Choice TAS founders Jacqui and Natalie Gray and DWD Tasmania.

Jacqui and Natalie were in the public galleries of parliament for every hour of the debate. Motivated

to campaign for law reform to fulfil the dying wish of their mother, Diane, who died from cancer in 2019, the women described the support for the law as "bittersweet".

“

The result... is a demonstration of just how much of a difference people power can make.

Jacqui and Natalie

The sisters had educated and mobilised the public, through the Your Choice TAS website, social media outreach and old-fashioned boots on the ground campaigning, which included storytelling, billboards, bumper stickers and the delivery to letterboxes of more than 120,000 information brochures.

They also championed a petition of 13,082 signatures in favour of legalising VAD, which was tabled in parliament by Greens leader Cassy O'Connor – a record number for a petition in the state.

Attention now turns to the Bill's third reading in the Lower House.

"We can't relax quite yet," the sisters said. "The debate resumes in March, following an independent University of Tasmania inquiry as requested by the Premier. Only then will the final vote take place."

An issue whose time has come

“In unequalled numbers, Australians support the idea that a dying person should be offered a choice about how much they need to suffer at the end of life.”

These words from Andrew Denton rang truer than ever in 2020 when three states nominated VAD advocates as finalists in their respective Australian of the Year awards.

Denton's nomination in NSW for Australian of the year, Dr Rodney Syme's nomination in Victoria for Senior Australian of the Year, and Belinda Teh's nomination in Western Australia for Young Australian of the Year represented a sea change in recognition of the need for more compassionate end-of-life choices.

Denton, 60, was nominated for his advocacy for better end-of-life choices including voluntary assisted dying, a cause close to his heart since the death of his father Kit in 1997 and the launch of Go Gentle Australia in 2016.

Dr Rodney Syme's nomination for Senior Australian of the Year was recognition of his voluntary assisted dying advocacy spanning over 40 years, and for his services to urology.

The Victorian Awards committee said: “Rodney has counselled more than 2,000 patients, risking prosecution and his reputation by assisting terminally ill Australians who wish to die with dignity.

“His book *A Good Death* recounts some of their stories. He also authored *Time to Die*, which argues for giving the right to assisted dying to those in unbearable pain. With compassion and care, Rodney helped frame the successful legislation of voluntary assisted dying in Victoria in 2017 and Western Australia in 2019.”

Belinda Teh's nomination recognised her leadership in the Western Australian voluntary assisted dying campaign, which saw WA become only the second state to pass a VAD law.

Rarely had someone personified and electrified such an important public debate like Belinda. She embarked on Belinda's Brave Walk, a 3,500 km trek from Melbourne to Perth to raise awareness of the desperate need for more compassionate end-of-life choices and to honour her mother Mareia, who died in agony from aggressive breast cancer in a specialist palliative care facility in Perth.

The WA Awards committee said: “Belinda shared her story many times, galvanising a groundswell of community support and inspiring people to be active in creating change. Belinda was instrumental in raising awareness about this issue, running a sophisticated

social media campaign, hosting public events and addressing supporters on the steps of WA Parliament House.”

Andrew Denton said: “The string of nominations reflects a shift in attitudes around the right of terminally ill Australians to decide for themselves how much they have to suffer at the end of life.”

This was despite repeated opinion polls over the past two decades showing community public support upward of 70%, Denton said.

“Now we have VAD laws in Victoria and Western Australia, proposed bills in at least three other jurisdictions and recognition for VAD advocates across the country.”



Five years ago, voluntary assisted dying was considered by many MPs as ‘a step too far’.



“

I am so proud of us as a community for the profound cultural change that has come to WA.

Belinda Teh

WHAT THE AWARDS COMMITTEE SAID:

Belinda was instrumental in raising awareness about this issue, running a sophisticated social media campaign, hosting public events and addressing supporters on the steps of WA Parliament House in Perth.

She also completed a 70-day walk from Melbourne to Perth in memory of her mother's suffering and to help convince MPs of the need for compassionate choice.

Belinda's advocacy saw the successful passage of voluntary assisted dying laws in WA.

“

The community is no longer asking their politicians to lead on this issue – they're asking that they follow.

Andrew Denton

WHAT THE AWARDS COMMITTEE SAID:

Andrew has led an intellectually rigorous debate in Australia about death and dying.

Drawing on his love for stories and 30-plus years in the media, Andrew has campaigned to introduce compassionate laws around voluntary assisted dying (VAD) that provide protections for the vulnerable.

His ground-breaking podcast series, *Better Off Dead*, covers the personal stories, moral arguments on both sides, and legislation from countries with VAD laws.

“

Providing a person with control is one of the most powerful palliative tools that medicine has.

Rodney Syme

WHAT THE AWARDS COMMITTEE SAID:

For more than 40 years, Dr Rodney Syme AM has challenged the laws on voluntary assisted dying.

Rodney has used media, parliamentary enquiries and seminars to help raise awareness about voluntary assisted dying – a cause rapidly gaining acceptance globally. With compassion and care, Rodney helped frame the legalisation of voluntary assisted dying in Victoria in 2017 and Western Australia in 2019.

Rodney has counselled more than 2,000 patients, risking prosecution and his reputation by assisting terminally ill Australians who wish to die with dignity.

Awareness and Health Promotion

Our mission is to improve the national conversation around death and dying, and in particular create an open dialogue about the need for kinder, more compassionate end-of-life choices.

The impact of COVID-19

In 2020, the restrictions imposed by the Covid-19 pandemic led us to do things a little differently.

By early March, it became clear that our focus had to be on staying safe and restricting the spread of the virus in the Australian community. We urged our supporters to follow reputable medical advice on hand hygiene, physical distancing and self-isolation and to stay connected with loved ones, particularly those who were elderly, frail or unwell.

We began working from home and limiting our public engagements. Although the circumstances were challenging, we remained optimistic and committed to protecting the most vulnerable in our society, the terminally ill, who needed our support more than ever.

Dying to Know Day

In July we held two webinars to mark Dying to Know Day an annual initiative of The Groundswell Project.

Campaign in Tasmania

In January, with plans for a private member's VAD bill in Tasmania, we implemented a new approach to campaigning, moving from "boots on the ground" to a more focused advisory role.

Throughout the year, we maintained close contact with Independent MLC Mike Gaffney, the sponsor of the bill, and

other MPs to ensure only evidence-based information reached the public domain. We also carried out a targeted social media campaign urging Tasmanians to contact their representatives.

Contact your MPs

With at least three state parliaments considering VAD bills, we relaunched our unique MP Look-Up Tool to encourage people to get in touch with their political representatives about VAD.

Custom built for GGA, the easy-to-use digital platform allows supporters to enter their postcode and access the contact details of their Upper and Lower House MPs (state and federal). It encourages supporters to write their own messages and to speak from the heart – a departure from the usual 'form letters' generated by other online platforms, and which are easy for MPs to ignore.

QLD parliamentary report and election

In March, we welcomed a Queensland Parliamentary Inquiry report into end-of-life choices, which recommended the government introduce a voluntary assisted dying law. The recommendation followed a year-long inquiry, which received more than 5,000 public submissions.

With the Queensland government postponing any action on VAD until 2021, attention quickly turned to the upcoming

state election and the make-up of the next parliament. We supported a targeted media and social media campaign urging Queenslanders to canvass their candidates' views on assisted dying and to vote accordingly.

Spinney Press

In February, we worked with Spinney Press to re-package GGA's evidence-based materials to make them available as a resource to Australian secondary school students.

Part of the Issues in Society series, the 64-page booklet 'Euthanasia and Assisted Dying', includes newspaper articles, online fact sheets, government report extracts and statistics, and opinions by commentators and lobby groups. Print and digital versions are available from the Spinney Press website.

Communicating our stories

Storytelling remains a crucial part of our mission.

Throughout 2020, the GGA website, Facebook, Instagram and Twitter platforms continued to be frontline resources to get our message out about the desperate need for VAD law reform.

Dying to Know Day 2020: Home Delivered

With voluntary assisted dying already a legal option in Victoria and soon to be legal in Western Australia, around 200 people registered for our first Dying to Know Day webinar in early July titled 'Voluntary Assisted Dying: Everything You Wanted to Know (but were scared to ask)'.

Participants were encouraged to put questions to an expert panel: 'What is it like for families to go through the process?' 'How are patients and loved ones supported through the various stages of illness, application and eligibility assessment, death and bereavement?' and 'What has been the impact on the medical professions?'

Providing insights were Jacqui Hicks and Nicole Robertson, whose mother Kerry

was the first person to use Victoria's VAD law; Dr Cameron McLaren, a medical oncologist who has helped dozens of Victorians to die under the law; and GGA's own Kiki Paul.

Our second webinar 'Living a Full Life While Planning for Death' in late July also attracted more than 200 people to hear a conversation between three Australians – Tanya Battel, Janet Cohen and Julian Henwood – about what it means to live with a terminal illness and why having a choice at the end of life is so important.

The webinars were a great success, with more planned for 2021.



Dying To Know day

SBS Insight

VAD: What doctors and patients think

In March, GGA worked with the SBS Insight program on a landmark episode on voluntary assisted dying.

Jacqui Hicks and Nicole Robertson featured prominently as panellists, telling the story of their mother, Kerry Robertson, the first person to make use of Victoria's Voluntary Assisted Dying Act.

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First-hand stories are 'kryptonite' to those who deny suffering at the end of life. Try as they might, they cannot wish other people's truth away.

The episode also featured the story of 90-year-old Laura Henkel, who travelled to Switzerland in late 2019 to access an assisted death. Laura's daughter Cathy Henkel, and granddaughter, Sam Lara, supported her decision and were by her side when she died.

"What Laura did was force us to talk about death and to talk about the end of life for the elderly and what options they do and don't have," Ms Lara said.

Other participants included Belinda Teh, who told of her mother Mareia's death from metastatic breast cancer in Perth in 2016, and Dr Cameron McLaren, a Victorian oncologist involved in numerous assisted deaths under the Victorian VAD legislation. Nia Sims, a Melbourne nurse living with the chronic and debilitating disease Scleroderma, appeared via video link.



Jacqui Hicks, Nicole Robertson and Dr Cameron McLaren on the SBS Insight panel.

These personal accounts of suffering at the end of life and the compassionate alternative offered by VAD stand as powerful refutation to those who continue to argue that voluntary assisted dying laws are unnecessary and unwise.

Research and Advice

As an expert advisory and health promotion charity, we promote information about end-of-life care based on established facts and peer-reviewed research. Our evidence-based interventions help to correct misinformation about end-of-life choices and provide valuable resources for medical, legal, political and community leaders.

Tasmanian campaign

From March, GGA provided Mike Gaffney MLC and other Tasmanian MPs with extensive advice and background materials to prepare them for the parliamentary debate on the End of Life Choice (Voluntary Assisted Dying) Bill.

NZ campaign

In 2020, New Zealand became the first country in the world to put the issue of voluntary assisted dying to a public vote.

We worked closely with the local Yes For Compassion campaign to provide evidence-based materials to help convince Kiwis to back the law in the referendum.

Despite a concerted campaign of misinformation by opponents, in early November referendum results showed two-thirds of Kiwis (65.1%) had voted 'yes' to the End of Life Choice Act becoming law. It will now come into force on 6 November 2021 after a 12-month implementation period.

Submission to the Queensland Law Reform Commission

In November, we finalised a 35-page submission to the Queensland Law Reform Commission (QLRC) outlining an appropriate legal framework for the state's proposed voluntary assisted dying law.

The issue had been referred to the QLRC by Premier Anastacia Palaszczuk after a parliamentary inquiry committee report in March recommended the state introduce a VAD law.

GGA recommended the QLRC follow the VAD model introduced in Victoria and soon to be implemented in WA, with some modifications to remove barriers to access for eligible Queenslanders.

Better Off Dead: Season 2

To mark the first anniversary of the implementation of Victoria's landmark VAD law we began interviewing for a second season of Andrew Denton's popular podcast series *Better Off Dead*.

Focusing on the experiences of those at the centre of the VAD pathway in Victoria, the podcast will be released in early 2021, ahead of parliamentary debates on proposed VAD laws in Queensland and South Australia.



Voluntary assisted dying is not, as some would paint it, a fringe social issue. It speaks to a core responsibility of any caring society: how we treat our elderly and our most vulnerable, the terminally ill.

Podcast

Better Off Dead Season 2: Casting light on VAD in practice

Over 18 months in 2014/15, our founder Andrew Denton, asked himself an important question: why are good people dying bad deaths in Australia, and why are there no laws to help them?

The result was a remarkable 17-part podcast called *Better Off Dead* which investigated the stories, moral arguments and individuals on both sides of the debate about euthanasia.

“I wanted to inform the debate and I wanted to inflame the debate,” Denton has said of the podcast. “I wanted politicians and doctors to stop sitting on their hands while Australians needlessly suffered.”

The podcast’s success led to a renewed push for voluntary assisted dying laws in this country.

In 2020, to coincide with the first anniversary of the start of Victoria’s landmark law, we began interviewing those directly involved: doctors, families of those who had died, and those tasked with making sure the law was operating according to the 68 safeguards agreed to by Parliament.

The result is a companion series to the original podcast, produced in conjunction with The Wheeler Centre and to be launched in early 2021.

Season 2 casts light on how the VAD law is working in practice – good and bad – and measures this reality against what was said during the parliamentary debate.

It also addresses some of the new claims made against Victoria’s law – often by the same people who so fiercely opposed its introduction in the first place – that

voluntary assisted dying has led to people rushed to their deaths without due care, and that palliative care has suffered as a result.

We believe it is instructive to compare these claims against the reality of the process of the law and the experiences of those who have actually used it. As Australia’s parliaments continue to grapple with the issue, it is important that their policymaking decisions are based on more than conjecture and hypotheticals.

In tandem with the Voluntary Assisted Dying Review Board’s regular reports, we hope that the podcast will help provide a better understanding of how the law is working, of who it works for, and of how it sits within our existing medical system.



“

Now, more than one year into the operation of Victoria’s law, it is possible to compare the hypothetical harms (and genuine fears) raised by MPs versus the actual experience of assisted dying.

Education

Good decisions at the end of life require access to reliable information. Creating trustworthy educational resources is central to our mission to spark better conversations about death and dying.

Educational materials

In August, we updated and republished our *Guide to the Debate Ahead on Voluntary Assisted Dying*, a user friendly summary of the main issues and questions raised during parliamentary debates on assisted dying.

Along with our e-books, films and other resources, including fact sheets and FAQs, the Guide helps to keep public commentary balanced and focused ahead of, and during, parliamentary debates on VAD laws. It and the other resources are free to download from the Go Gentle Australia website.

Countering misinformation

GGA believes it is essential to respond quickly and robustly to the most egregious and misleading public statements about VAD.

In July, we published an analysis of a book circulating in NZ ahead of that country's referendum on VAD. Its author, former journalist Caralise Trayes, said her book was a balanced investigation of the pros and cons of assisted dying that would help educate Kiwis about assisted dying and arrive at "the truth".

A closer examination, however, sparked doubts about Trayes' claim to be an independent observer. She had failed to disclose – in her book or in subsequent media interviews – her close association with a Pentecostal church that was strongly opposed to assisted dying. More fundamentally, Trayes' book focused almost entirely on spurious arguments against VAD, with 17 of 21 interviews focusing on avowed VAD opponents.

In August, we collated a response to the Australian Care Alliance (ACA's) allegations of so-called wrongful deaths involving VAD. The response is designed to be read in tandem with our earlier publication *The Full Picture*. It establishes that the ACA's case studies rely

overwhelmingly on omission of crucial facts, half-truths, and unsubstantiated information.

In November, we published the response as a briefing document for Tasmanian MPs ahead of the debate on the End of Life Choice Bill (2020) in the Lower House.

Defending Victoria's law

In August, GGA led a response to an article critical of Victoria's VAD law written by palliative care specialist Dr Odette Spruijt and published by the Australian Medical Association on a digital platform with wide readership within the medical profession.

While we believe the Victorian law's operation should be thoroughly scrutinised, we also believe critiques should be in good faith and based on evidence and facts – not dogma.

We pointed out Dr Spruijt's links to organisations that are philosophically opposed to VAD and highlighted her misrepresentation of statistics from Canada's assisted dying regime. We also challenged her unsubstantiated assertions that assisted dying had become "routine" and that VAD requests could be taken "at face value and acted upon" without a mental health review or access to palliative care.

'Baseless and hurtful' claims

In September, we assisted the family of an elderly Victorian woman who chose to end her life through voluntary assisted dying to respond to an online article that grossly misrepresented her death. Written by a distant family member with no knowledge of the woman's end-of-life circumstances or wishes, the article was described by the family as "baseless and hurtful". It was subsequently taken down from the publisher's website after GGA's intervention.



Dr Kristin Cornell with her father Allan, who elected VAD when his suffering from MND became intolerable. Despite access to expert assistance, Allan faced many hurdles. Kristin says: "We can do this better. It shouldn't be so hard that one is tempted to give up." Photo supplied.

VAD in Victoria

A law working safely and as intended

The Voluntary Assisted Dying Review Board's first full-year Report of Operations on Victoria's VAD law showed that the legislation was operating safely and as intended.

The Review Board said that since 19 June 2019 (when the Act commenced), 348 people had been assessed for eligibility to access voluntary assisted dying and 231 VAD permits were issued.

124 people had gone on to use the VAD medications, representing just 0.29% of all deaths in Victoria over the year – a tiny proportion.

Four in five of those who took the medications had end-stage cancer, and their median age was 71.

Compliance with the Act sat at 99%. Only one application was deemed non-compliant and the Board stressed this was due to an issue in the paperwork, not eligibility.

The Board also noted a 50% increase in the number of eligible applications over the second half of the year, confirming what was already known – that there is desperate need in the community for a more compassionate end-of-life choice.

The Review Board's conclusions reflected GGA's own research into the operation of the Victorian law, including detailed interviews with medical professionals and family members of people who had elected to pursue VAD.

Universally, the families we spoke to were grateful that

their loved ones had the option to limit their suffering at the end of life. All of them spoke to the humane, yet rigorous, application of the law from everyone involved: doctors, nurses, pharmacists, medical institutions, and the VAD care navigators.

We welcomed the Board's canvassing of ways to improve access for eligible Victorians, including a call to amend a Commonwealth law that prohibits the use of telehealth in VAD. Like the Board, we remain concerned about the impact the criminal code's prohibition on the use of telehealth is having on people in the regions.

“

The past six months continues to highlight the compassion and relief Victoria's voluntary assisted dying scheme is providing to terminally ill people, their friends and family.

VAD Review Board

We will continue to push for even more information in future reports, including data on where people are choosing to die, what end-of-life care they are receiving, the average time between receiving the medication and using it, and for how many people it arrives too late.

Operations

Our staff, resources and funds all work towards achieving our mission and objectives – to spark a better conversation around death and dying, and to help relieve distress, helplessness and suffering at the end of life.

Technology

For a small team working in the not-for-profit space, working effectively and with impact depends on having the right technology at hand. After reviewing our existing platform, which was designed for US-style campaigning, we are investigating a new platform designed and supported in Australia specifically for the charity sector.

New office

Having outgrown our first shared office space, in December we began the process of moving to a larger shared space in central Sydney.

Philanthropy and fundraising

Despite a challenging fundraising environment imposed by Covid-19, we continued to build relationships with key philanthropists who understood the importance of GGA's ongoing work. We were delighted to secure further contributions that will help ensure our long-term future.

In May, we rolled out our end-of-financial-year fundraising campaign, featuring GGA supporters Janet Cohen and Victorian oncologist and VAD physician Dr Cameron McLaren. We made a strategic decision to postpone or cancel other public fundraising initiatives and we were pleased to raise close to \$20K in our only official fundraising campaign for the year.

Supporter Survey

Let's Talk About Death

Is talking about death easy or hard, and what tools might make the conversation easier?

In April our Let's Talk About Death mini-survey of supporters revealed some interesting things – not the least that death may not be the 'taboo' subject everyone once believed.

From the 1,023 responses, 83% said talking about death was either easy and conversations had already taken place, or not easy but necessary. Some 14% said it was hard, and they could do with some help. Only 16 respondents (1.5%) thought the subject was too hard.

Supporters said the resources that would most help them initiate end-of-

life conversations were fact sheets (23%), a dedicated website (18%) and workbooks with information (12.5%).

On the subject of what topics they would most like to see information about, voluntary assisted dying was the clear preference, followed by advance care planning, power of attorney and medical treatment options.

We'd like to thank everyone who took the time to complete the questionnaire. The responses will help us create our next generation of tools and resources, and are essential if we are to fulfil our mission to improve the national conversation around death and dying.

1,023 responses

83% – talking about death was easy or had already happened

14% – talking about death was hard and they could do with some help

1.5% – the subject was way too hard

Factsheets and a dedicated website were the most helpful resources for end-of-life discussions

Financial Report

For the year ended 30 June 2020

Consolidated Statement of Surplus or Deficit

	2020	2019
Assets		
Current Assets		
Cash on hand	271,206	556,776
Receivables	4,206	14,746
Other	7,664	7,664
Total Current Assets	283,045	579,155
Total Assets	283,045	579,155
Liabilities		
Current Liabilities		
Payables	10,398	26,380
Total Current Liabilities	10,398	26,380
Total Liabilities	10,398	26,380
Net Assets	268,887	552,775
Equity		
Current year earnings	(283,888)	401,961
Retained surplus	552,775	150,814
Total equity	268,887	552,775

Consolidated Statement of Financial Position

	2020	2019
Revenue	698,703	870,745
Administration expense	66,938	49,013
Program delivery costs	816,263	304,279
Employee benefits expenses	99,390	115,492
Current year surplus before income tax	(283,888)	401,961
Income tax expense	-	-
Net current year surplus	(283,888)	401,961
Other comprehensive income	-	-
Total comprehensive income for the year	(283,888)	401,961

In Remembrance

Vale Rhonda Taylor and Colin Clarke

We lost two remarkable VAD advocates in 2020.

In March, Rhonda Taylor (pictured right) a much loved and fearless public face of the campaign in Western Australia, died of metastatic breast cancer in Perth.

In June, Colin Clarke (pictured below) an emergency doctor of 20 years, died of mesothelioma, also in Perth.

Rhonda, who had lived with cancer for many years, became one of the public “faces” of the push for law reform in WA when she courageously told her story to media. She knew the WA laws would not come in time to help her, but that they would offer an incredible comfort to others. A petition in her name calling on MPs to stay the course and pass the law collected more than 50,000 signatures.

There is nothing gentle about mesothelioma. At the height of its ravages, Colin – and his wife Lizz, a nurse – took precious time to try and help Western Australia’s MPs understand why there was a need for a VAD law.

Their messages – in writing, in interviews, in a video, and, finally, addressing a rally on the steps of WA’s Parliament House – were compelling and human, and all the more



powerful for being steeped in deep medical experience. They spoke of the death that Colin inevitably faced. The death that he didn’t want to put himself or his family through.

Both Colin and Rhonda received the best of care in their final days but, tragically, for Colin this was not enough. What he and Lizz feared came to pass.

It is difficult to overstate the courage, and the sheer humanity, that both Rhonda and Colin displayed.

Shortly after Colin’s death, Lizz gave us permission to reprint a small piece she wrote describing what those last days were like for the husband, father, brother, and son, who she loved. You can read Lizz’s words on the page opposite. It is a powerful explanation of the limits of medicine – and the need for VAD choice, and we promised that, wherever and whenever VAD was debated, we would make sure Lizz’s words are heard.



Still We Wait

I'm so angry at the inevitability of what's happening. Last week, this lovely man whilst terminally ill and accepting of the restrictions imposed on his body by cancer, was able to chat to his children, watch movies with them and eat a simple meal.

The ravages of this cancer are all too apparent. We moved into a hospice two days ago, I can no longer maneuver him alone. We both need the help. We all know that death is near, he has no respiratory reserve. He tells us "I want to die". "This isn't what we wanted".

But still we have to wait.

It's clear that he will get an infection. Most likely in his chest, because he aspirates gastric fluid several times a day. Or maybe at one of the numerous drain sites littering his abdomen where fluid build up has been drained. Sometimes four litres at a time.

It is clear he will get an infection. But still we wait.

We wait for the infection to take hold, to make him sicker.

We wait for delirium and incontinence, it's par for the course.

And yet still we wait.

We wait for his organs to stop working, for the skin injuries to become more painful.

We hear the rattle of sputum. He no longer has the reserve to move it from his lung.

We know it's a good reserve for bacteria, and yet still we wait.

We wait for this young man, their father, my husband, both a big and little brother, and son to his anxious parents watching close by. We wait.

We wait for all traces of independence to be lost. Dignity and privacy are preserved outside the room. The kindness of everyone in this place is unquestionable and reassuring. But here, he is laid naked to unfamiliar hands. Personal care is no longer that, but remains necessary. But still we wait.

I'm angry. I ask why we have to wait? His wishes were well known and documented. Why it is that we can sedate and wait, but we can't add just a little more of that or this drug. Stop this now? But still we wait.

We watch his personhood leave the room, but we wait for the final indignities. One more change and refresh, one more time being rolled with unfamiliar hands on skin. One more reassuring touch to his arm, empty in its promise. Yet, still we wait.

Why? For what purpose? To prolong this inevitable end? To extend the indignities a little longer?

And yet still we wait.



Lizz Clarke,
June 2020

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And with special thanks to

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Go Gentle Australia is an expert advisory and health promotion charity founded by Andrew Denton to spark a national conversation about end-of-life choices, including voluntary assisted dying. Our focus is on promoting evidence that is based on established facts and peer-reviewed research.

Cover photography (left to right) Melissa Mills, Shayne Higson and Simon Schluter/The Age.

First published in March 2021.

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Go Gentle Australia has been established to help relieve the distress, helplessness and suffering experienced by Australians with untreatable or terminal illnesses, their families and carers.

If you would like to learn more, visit us at gogentleaustralia.org.au

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Go Gentle Australia Limited is a registered charity.

Go Gentle Australia is a health promotion charity founded by Andrew Denton. It was established to help relieve the distress, helplessness and suffering experienced by Australians with terminal illnesses, their families and carers. We are about a better conversation around death, dying and end-of-life choices, including voluntary assisted dying.