

ACHLR oration

There's an old joke, a near-perfect one-liner: "I'd like to die peacefully in my sleep, like my father. Not screaming in terror like his passengers".

No one wants to die screaming.

For decades now, opinion polls have shown more than 70% of us support assisted dying choice, regardless of how old we are, who we vote for, or what God we follow.

But if it's such a no brainer, how could VAD law fail to pass in Australia, over two decades and more than 50 attempts in different states? And when it did – in Victoria, in 2017 – why then?

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Before I attempt to answer those questions, let me explain how I got here. 25 years ago, I watched my own father die painfully over three days. This happened in our local hospital, and despite the best of care.

Kit was 67, and though clearly dying of heart failure, and obviously in great pain, he was assisted to die in the only way that Australia's law then would allow: He was given ever-increasing doses of sedatives, to settle the pain. Only morphine never did settle the pain. Not his and not ours. The images of those final days will never be erased.

So profoundly shocking was that experience it would be almost twenty years before my sisters and I spoke about it, and never with our mum.

So, in 2015, having sold my production company and stepped away from the media, I set out to answer the question: 'why are good people are being forced to die bad deaths in Australia?'

To do this, I spent thousands of hours, over 8 months, criss-crossing Australia and travelling the world, recording conversations with doctors, nurses, politicians, ethicists, priests, and lawyers on all sides of this question. Above all, I spent time with the terminally ill and their families – their willingness to share the intimacy of dying a privilege I will carry with me always.

I turned it all into a podcast -- 17 episodes in all - called it '**Better Off Dead**', looking at the arguments for and against voluntary assisted dying.

Along the way, I discovered things about the politics of dying in Australia which deeply troubled me. Which trouble me still.

- I heard, personally and at parliamentary inquiries, of people begging for extra pain relief, but being denied it; or starving and dehydrating themselves to near-skeletons to hasten their deaths, as their families watched; or rationally requesting help to die

as a response to terrible suffering, but being referred to a psychiatrist instead; or - rather than facing the ravages of their inevitable decline - taking their own lives using ropes, knives, poisons ... even nail guns.

- I heard senior doctors (almost always of faith, but never declared) front those same inquiries and reassure politicians, either that they had never seen such suffering, or that it need never happen if only palliative care were given more resources – a claim directly refuted by Palliative Care Australia’s own words and statistics.
- I heard breathtaking examples of medical paternalism, none more striking than the geriatrician who, when confronted at an AMA panel discussion with the overwhelming level of public support for assisted dying, responded: ... *that's why we're the profession ... we get paid \$200,000 dollars a year to make these sorts of decisions. That's why the community gets it wrong.*
- I learnt of the high levels of futile care doctors inflict on people at the end of life; Of a survey of Queensland doctors which showed that, for a majority, it was easier to keep treating people than to ‘have the difficult conversation’ about dying; Of a study of oncology patients notes in Victoria looking for any patient-centred words—comment, not about their white cell count, but about what mattered to them – and finding them only in five per cent of those notes.
- I learnt of the dominance of Catholic Health in our end-of-life care – providing almost 60% of Australia’s palliative care services – and of their uncompromising philosophy about people’s choices as they die. In the words of The Vatican: *Euthanasia... is an intrinsically evil act, ... that no end can justify ... To end the life of a sick person.... is to take the place of God in deciding the moment of death.*
- I discovered a community of Christian doctors – many of them the same ones who appeared at parliamentary inquiries to argue against VAD– talking about how the Bible instructs that ‘*our lives are not our own*’, and of how suffering provides ‘*an opportunity for growth*’.
- I learnt that theirs was largely a self-regulating system. The use of terminal sedation in hospitals, for example – when a doctor decides to ease a dying person’s suffering by drugging them into a coma from which they are unlikely to awake – was unregulated, with no guidelines, and no central records kept. Doctors could do as they saw fit, without scrutiny, the law giving them complete power to treat according to their personal beliefs, some of which involved never – under any circumstances – hastening someone’s death. These were doctors for God, seeking to preserve laws which enabled them to be doctors *as* God.
- Most disturbingly of all, I heard from families whose loved ones had been treated by some of these doctors, and who had suffered horrifically as they died. When I put these testimonies to the doctors for comment or correction, I was met with silence.
- Finally, I learnt that the lobbying by these doctors, and their willingness to propagate the untruth that, properly funded, palliative care makes VAD unnecessary, had real political and social consequence

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Let me jump to 2016. Following the release of ***Better off Dead***, I launched the national advocacy group ***Go Gentle Australia***. Our goal was to level the VAD playing field, by fighting

for the interests of the terminally ill and their families against those of powerful groups such as the Church and Australia's peak medical body, the AMA. To do this, we would bring in media, political, research, and advertising, professionals who knew how to campaign, and to create pressure for change.

Go Gentle's publicly stated aim was to see VAD made legal around Australia so that ...

- **We have a legal right to be protected from unnecessary suffering at the end of life**
- **And that doctors can be protected in law, and guided by regulation, when doing what many currently do in the shadows**

Our internal operating policy was more succinct: ***No stone unturned. No turd unstoned.*** In pursuit of this, we methodically chased down every bit of misinformation put forward by opponents of VAD that we found, and which often ended up in parliamentary debates. This 'myth-busting', as we called it, offered politicians, instead, credible, reliable, peer-reviewed, evidence showing that similar laws overseas were working well, and as intended.

Increasingly over the years, one of the key sources for that evidence has been QUT's Centre for Health Law Research, and I'd like to take this opportunity to commend Professors White and Wilmott, and their team, for their commitment to evidence-based policy making.

Of course, we were far from alone. State-based Dying with Dignity groups who'd battled for law reform for years; as well as doctors, nurses, politicians, and families who'd been through the same hell as mine (or worse); were standing up all over the country to be heard. So, too, Queensland's Clem Jones Trust, who gave us significant financial support in our early years.

Our first campaign was in South Australia in 2016, where I quickly came to understand the old saying '*there are two things in life you should never see being made – a sausage and legislation*'.

It's worth looking at what happened there, because it has all the elements which explain why 51 attempts at VAD law reform across Australia had failed in the 20 years since the world's first such law - the NT's *Rights of the Terminally Ill Act* – had been controversially abolished by our Federal Parliament, using its constitutional power to overrule Territorial law.

On the surface, the *South Australian Euthanasia Bill, 2016* had strong prospects of success: It was supported by both the Premier and the Leader of the Opposition. It was coming before a Parliament which had debated this issue 14 times, more than any other in Australia. It had very strong media and popular support. Crucially, it also had the active, boots-on-the-ground support of the nurses' union, whose members took it upon themselves to meet with MPs and explain why they should support the legislation. As well, the local advocacy group, the South Australian Voluntary Euthanasia Society, had spent many years campaigning publicly, and lobbying politicians, for reform. Finally, there had been two significant developments overseas, with Canada, and America's most populous state, California, both passing right-to-die laws in 2016.

So why did South Australia, like all the other attempts before it, fail?

As I dived deep into the lobbying and legislative process, I identified four key areas which led to the defeat of the Bill.

Firstly, it was a Private Members Bill Although the co-sponsors were MPs Steph Key, from Labor, and Duncan McFetridge (Liberal) – and even though they had the support of their leaders – both were backbenchers with few resources and limited political heft. As the campaign intensified, they found themselves struggling to match the combined power of their opponents, led by seasoned campaigners from the Catholic Church, the AMA, Palliative Care Australia, and many within their own parties, some of whom held key positions such as Party Whip and Speaker of the House.

Secondly, the Bill was based on a poor political and communications strategy. In fact, South Australia's politicians were asked to consider *two* Bills in 2016, containing significant philosophical and practical differences. The first, put forward by Steph Key, was largely based on European voluntary euthanasia laws that had been operating in The Netherlands and Belgium since 2002. These were based around the concept of 'unbearable and hopeless physical or mental suffering', which could encompass diseases such as Alzheimer's or psychiatric conditions, and which did not require the condition of the person seeking to use the law to be terminal. In other words, they could be assisted to die many years before they may do so naturally.

While there were (and are) strong philosophical and medical arguments for such a law, they did not take into account our parliamentary reality – which is that we have (other than in Queensland) is two legislative chambers, filled with MPs of varying beliefs, capacities, and willingness to engage on this issue, a majority of whom had to be persuaded to pass a highly controversial, indeed historic, piece of legislation, and most of whom firmly represent an orthodox Judeo-Christian view of the universe. As Go Gentle began to engage with South Australian MPs on this issue – and we spoke directly with more than 80% of them – it became clear that many of them did not understand, and were uncomfortable with, this European-style law. For us, a basic political principle began to emerge: *If a politician can't explain the bill to themselves, what chance do they have of explaining it to their electorate?*

As the reality dawned that Steph Key's legislation didn't have the numbers in the house, it was withdrawn and replaced by a Bill put forward by Liberal Duncan McFetridge, which was much more closely based on laws that had been running in North America since the late 1990s. More conservative than the European model, to be eligible, a person had to have a 'terminal medical condition' which was causing 'intolerable suffering', with a 6-months prognosis, determined by two doctors, until death. The Bill explicitly stated that mental illness or disability, alone, were not eligible conditions.

While these changes did bring some MPs inside, they came far too late. Indeed, the final shape of the Bill didn't circulate until hours before debate was due to start in the house. This meant that many MPs approached the debate unsure, unclear, or unconvinced, that the legislation before them was properly thought-through.

It also put them in the position of trying to understand what the bill was about in the middle of a tired and emotional debate at 2am.

And it allowed opponents, not unfairly, to characterise the legislative process as confused and chaotic.

To our eyes, the failure to have a strong, politically realistic, narrative from the start – and to prosecute that - was the single biggest reason for the loss of the Bill. But there were two other contributory factors:

One being, that the Bill was subject to a powerful campaign of Fear Uncertainty and Doubt, also known as FUD. As part of my research for the *Better Off Dead* podcast I had attended an international anti-euthanasia convention in Adelaide the year before. There I heard campaigners from around the world spell out strategies which had been successful in stopping VAD legislation. One was US legislator Nancy Elliott, spelling out how to get MPs to vote no:

‘We have to be flexible,’ she said. ‘When you have lots of arguments. If one argument gets blown out of the water, you still have more. And each argument will reach somebody else. You only have to convince legislators that they don’t want this bill. I mean, you don’t have to win their hearts and minds. All you have to do is get them to say, ‘Not this bill.’ And then you’ve got your win.

The ‘not this bill’ strategy was clever. Sow one seed of FUD in a politician’s mind, and you can reap a harvest of hesitation.

I saw this play out, first hand, in the South Australian Parliament in 2016. Watching Duncan McFetridge, standing on his feet for almost 12 hours, trying, with increasing desperation, to respond to endless hypothetical scenarios about the law he was proposing, was like watching a juicy seal slowly singled out by a school of sharks.

Here is a list, by no means exhaustive, of some of the arguments run against his Bill in that debate:

It’s a slippery slope – today, it might be for terminally ill adults, tomorrow it will be for children; it’s wide open to elder abuse; it threatens people with disability; it will lead to people being coerced to die against their will, or being encouraged to die because they are a burden; it sends the wrong message to young people about suicide; it goes against the Hippocratic oath of doctors to ‘do no harm’; it will destroy the doctor-patient relationship; it will damage palliative care; it is unnecessary because palliative care can deal with all pain; it will threaten indigenous Australians; it will lead to people being killed without their consent; it will encourage suicide tourism; it will open the door to ‘euthanasia enthusiast’ doctors; it will be a danger to people who are depressed; it will encourage doctor shopping by the terminally ill;; it is impossible to accurately diagnose if a person is ‘terminal; it’s an attack on society’s core belief in the sanctity of life; it can never have enough safeguards; it has

so many safeguards this proves it can never be safe; and – of course – it means that South Australia will turn out like Nazi Germany.

By 3.30 am when his Bill was voted down by just one vote, that of the deeply Christian Speaker of the House Michael Atkinson, Duncan cut a figure of such dejection it was hard to watch.

The final factor which contributed to the failure of the 2016 Bill was the crucial role played by influential forces within South Australia's medical community.

While Netherlands law had, to a large extent, been prompted by doctors seeking legal guidance and protection to do what they were already doing covertly - which was assisting patients suffering unbearably to die - in Australia, the situation was very different.

Other than the nurses' union, not a single peak medical body in Australia supported VAD in 2016. Indeed, most were openly hostile to it. Although the mantra of 'patient centred care' was widely used by the medical profession, in truth it was still rife with paternalism and a strong tradition of 'doctor knows best'. Doctors who did speak out in favour of patient choice through VAD were often ostracised. All this, of course, was amplified by the strong influence of the Catholic and Anglican churches, particularly in end-of-life care.

One example of how this came to bear on the South Australian result stands out:

The day before the parliamentary debate representatives of Palliative Care South Australia went to Parliament House to brief MPs.

According to notes made by a staffer who attended the meeting one MP told the palliative care delegation:

It has been put to me that some people can't be treated with palliative care.

To which they responded: *What we can't deal with is the existential distress. From the symptom perspective, with palliative sedation as the fall back, we can control everything.*

As mentioned earlier, this was untrue. Research commissioned each year by Palliative Care Australia showed that somewhere between 4-5% of patients died with extreme symptoms of pain and suffering despite optimal care.

But it was an untruth that hit its mark. One of the MPs at that briefing was then Attorney-General, John Rau, who had indicated his cautious support for the legislation.

As the debate wound into the early hours of the morning, it was Rau who dramatically crossed the floor at the last minute to tie the vote, which would then be voted down by the Speaker.

Speaking after the vote, Rau gave as his reason this:

In the end, I'm not convinced that there's a substantial group – or even a small group – of people who are not able to be adequately comforted by palliative care.

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If South Australia in 2016 was a case study in political and strategy failure, in almost every respect, Victoria in 2017 was its opposite.

Unlike South Australia, where the ad hoc and chaotic way in which legislation reached parliament created uncertainty amongst MPs, Victoria's legislation was built on widespread consultation across all stakeholder groups.

In May 2015, a cross-parliamentary Inquiry into End of Life Choices was appointed, chaired by Liberal MLC Ed O'Donohue. After 10 months, 17 public hearings, and the receipt of more than 1,000 submissions, its final report in June 2016 found the following:

- Repeated examples of inadequate pain relief being delivered to dying patients by doctors for fear of breaking the law.
- The inability of palliative care, despite its many benefits, to relieve all suffering.
- People being put on trial, but being given no custodial sentence, for helping those they love find a merciful end.
- Doctors being forced to break the law in order to help their patients die, but having to do so without support, regulation, or accountability.
- Trauma experienced by families watching seriously ill loved ones' refuse food and water to hasten death and finally relieve their suffering.
- People experiencing an irreversible deterioration in health taking their own lives, often in horrific circumstances.

Commenting on existing end-of-life law, the Committee concluded that:

'maintaining the status quo [is] an inadequate, head-in-the-sand approach to ...the plight of the Victorians discussed in [this] Report'.

Along with improvements to palliative care, they recommended by 6-2 that VAD be made legal in Victoria.

Six months later, Victoria's Premier Dan Andrews announced that his government intended to put forward legislation: the first time a Government Bill for VAD has been put in Australia (others had largely been Private Members Bills). The significance of this – in both symbolic and practical terms – cannot be overstated.

Although still a conscience vote, it meant that the principle of legislation has been backed by a majority of cabinet. It also meant that the resources of Government could be brought to bear in drafting, then advocating, the Bill, and also in negotiating to win over wavering votes.

A clear example of this was the immediate establishment of a Ministerial Advisory Panel to determine how voluntary assisted dying would work in practice. The Panel, chaired by former AMA President, Professor Brian Owler, and including respected representatives from palliative care and the disability communities, received 176 submissions and held forums and roundtables with more than 300 stakeholders. Their final report in June 2017 recommended a framework that attempted to balance access with oversight to guarantee community safety.

In sum, to be eligible you had to be 18 years or older, mentally competent, and diagnosed with a disease, illness, or medical condition that is incurable, advanced, progressive and is expected to cause death within less than 12 months; You also had to be experiencing suffering that cannot be relieved in a manner you considered tolerable. Disability and mental illness alone could not make you eligible.

Safeguards included the requirements for two written requests from the patient, two doctors to sign off on the process, and a ban on doctors suggesting voluntary assisted dying.

The government legislation that followed, incorporated all 68 safeguards recommended by the Panel, and was touted by the Premier as the 'safest and most conservative in the world'

Nowhere was the value of a government bill more evident than in the parliamentary debates. Brutal affairs - the one in the Lower House went for 24 hours, in the Upper House, 28 – nonetheless they stood in stark contrast to what I'd seen in South Australia. There, Duncan McFetridge had flailed for 12 hours trying to answer detailed, and sometimes impossible, questions. In Victoria, when Health Minister Jill Hennessy and Special Minister of State Gavin Jennings, were faced with the same barrage of detail and dark hypotheticals, they had staffers from the Department of Health supporting them throughout with responses and rebuttals. Although fiercely contested, at no point did the passage of the Bill falter.

And when, having passed the Lower House (where the government had the numbers) unamended, it became clear that concessions would need to be made in the Upper House (where the government was in minority) for the legislation to pass, they agreed to reduce the eligible time frame from 12 months to 6 months (with exemptions for people with neurodegenerative conditions), and to increase funding for palliative care in regional areas. In the end, this was enough to lock in a majority: In November 2017, the Victorian Parliament passed the Voluntary Assisted Dying Act. It had passed the Upper House by just 4 votes.

By following such a long and consultative process, Victoria's parliament successfully negated three of the most powerful arguments against VAD which had prevailed in other states.

The first, that **fully funded palliative care made VAD unnecessary**, was exposed as untrue, both by the searing personal testimonies given to the parliamentary inquiry, and by the presence of three of Australia's most respected palliative care figures on the expert panel.

The second, **that VAD law will inevitably lead to a slippery slope**, was strongly rejected by the cross-party committee, five of whom broke new ground by going to countries where assisted dying laws exist to see for themselves their impact. What they found was – quote – **‘rigorous safeguards, monitoring procedures and high levels of compliance sitting within robust regulatory frameworks’** and **‘no evidence of the often cited ‘slippery slope’**.

And the third, the idea that **‘legalising VAD is a Rubicon no society should cross’**, best expressed by Paul Keating who wrote: *‘No matter what justifications are offered for the bill, it constitutes an unacceptable departure in our approach to human existence.’*. In laying bare - with evidence from families, doctors, palliative care physicians, nurses, coroners, and first responders – the deficiencies in Victoria’s existing law, the Committee asked of the parliament a new question. Not Keating’s *‘how can we consider doing this?’*. Instead, *‘based on this evidence, how can we not?’*

Almost a year later, a joint study by the “right-wing” Institute of Public Affairs and “left-wing” Per Capita Australia think-tanks investigated 20 government policy decisions to assess which had demonstrated the greatest degree of evidence-based policy making.

Coming in at the top, with a score of 9 out of 10 categories, was Victoria’s VAD law.

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There were other, less tangible reasons, Victoria’s law succeeded where others failed. Not least, a remarkable constellation of significant individuals whose paths crossed at just the right moment. Chief amongst these were the late Dr Rodney Syme, who, along with his bold public advocacy for VAD, spent years quietly educating Victorian MPs of the need for the law. Then there was Professor Brian Oowler, who broke with the hardline opposition of the AMA to help write, and then steer, Victoria’s law. There was Coroner John Olle whose evidence to the parliamentary inquiry about the brutal suicides of the terminally ill happening every week in Victoria was a game-changer. And finally, there was Health Minister Jill Hennessy. As well as being a formidable parliamentarian, Jill had a commitment to seeing this legislation pass far beyond political philosophy. Not only had she watched her mum die, painfully, of MS but, even as she was standing in parliament for close to 24 hours, arguing for the law, her dad was dying of cancer. She had been to visit him the morning of the debate. Unable to speak, he held up a sign. It read “give me the Hennessy”. Her dad was begging relief from a law which did not yet exist, but which, thanks to his daughter, soon would.

The Rubicon which would swallow both her parents in its merciless wash had indeed been crossed.

Within four years, much of Australia would follow.