

The case for assisted dying

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STORY: VICTORIA LAURIE

Clive Deverall was a champion for palliative care. But, as a cancer patient in ‘every kind of pain’, he took his own life.



On state election day in Perth this year, Clive Deverall decided it was the right time to end his life. It would be a form of protest against the Liberal state government, which he felt was obstructing assisted dying laws, and a pointed message to Premier Colin Barnett, who opposed voluntary euthanasia. As it turned out, March 11 proved as fatal for Barnett’s reign as Deverall’s final violent act in a public place where he knew his body would be found quickly. By his side he had left a note, which ended: “Suicide is legal, euthanasia is not.”

Deverall, 75, well understood the politics of his actions — as head of the Cancer Council of WA for more than two decades, a former president of Palliative Care WA and more recently a euthanasia advocate, he was on first-name terms with many of the state’s senior doctors and politicians. But he had experience as a patient, too, through his own gruelling battle with cancer.

His posthumous protest note has now prompted Deverall’s widow, Noreen Fynn, to talk about his life and death. She’s heard all the arguments for and against a law that would permit voluntary euthanasia, but there is one salient fact she can’t avoid. “If there had been voluntary euthanasia legislation, Clive would still be here,” she says, her soft voice inflected

by a faint trace of her African birthplace. “He would have known that he had the ability at a later date to pick up a drink of some sort [to end his life]. He wouldn’t have needed to do what he did. He went far too early, and to me that was a real tragedy.”

When her grief subsides, Fynn will add her voice to those Australians who want to be able to choose the day and manner of their own deaths, as occurs in the Netherlands, Belgium, Luxembourg, Switzerland, Colombia, Canada and a handful of US states. Momentum is building and euthanasia advocates believe Australia is closer this year to legislation than in any year since Federation. At least two states — NSW and Victoria — are in the throes of serious debate and drafting euthanasia legislation, and WA’s new Labor government is promising a similar move. As Go Gentle Australia founder and TV documentary maker Andrew Denton puts it, “2017 is a year of great promise for anyone who supports the choice of voluntary assisted dying”.

Denton, whose father Kit died racked with pain in 1997, launched Go Gentle in South Australia last September, shortly before the state came within one vote of passing a Death with Dignity Bill. With 23 votes on each side, the 15th attempt in the state’s history to pass such a law was lost after the Speaker cast a vote against it. Tasmania’s parliament voted down a Voluntary Assisted Dying Bill 10 days ago. In Victoria, the issue is likely to be decided later this year. Premier Daniel Andrews and health minister Jill Hennessy say Victorians are entitled to high quality end-of-life care that includes the option of assisted dying “for those with a terminal illness who are dealing with unbearable suffering”. Andrews’ views changed after his father died from cancer in April last year. “My family has gone through something that many families go through,” he said in December when announcing the assisted dying bill. “That gives you reason to reflect and ... to reassess whether you’ve got this right. I will vote to give Victorians a choice at the end of their life.”



Andrew Denton.

In NSW, a parliamentary group is working on a bill that could be introduced soon. Western Australia's euthanasia proponents hope for a bill and a conscience vote later this year. And in federal Parliament, several senators are trying to overturn the Kevin Andrews-initiated Euthanasia Laws Bill that, in 1996, killed off Australia's first euthanasia law in the Northern Territory a mere nine months after it was passed.

The gathering momentum came too late for Clive Deverall. As the dynamic head of the Cancer Council in WA from 1977 to 1999, he helped people seeking expert end-of-life care almost daily. "He was a colossal spirit who would not give up," says research director Terry Slevin, who describes his friend as wry, humorous and a sceptic who fought back hard when targeted by peddlers of bogus cancer treatments, asbestos products, solariums and tobacco. "One legend has it that bullet holes were found in his car around the time Clive was making life uncomfortable for the asbestos industry," recalls Slevin. "But Clive back down? Never!"

He says Deverall railed against doctors who swept death under the carpet. He urged people to face up to death's inevitability; he promoted the idea of advanced health directives and in 2010 asked then state health minister Kim Hames to witness his own "do not resuscitate" directive. "I told Clive, 'I'm glad you've written it all down because I'd want to save you,'" Fynn recalls.

Yet Deverall was equally supportive of palliative care. He promoted home-based palliative care in WA and pioneered the building of the state's first purpose-built hospice for the dying. For his efforts he was awarded an Order of Australia, a state Centenary Medal and an honorary doctorate from Curtin University.

When he met social worker Noreen Fynn in the early 1990s, the two divorcees were instantly attracted. But in 1994, Clive was diagnosed with a rare form of the blood cancer Non-Hodgkin lymphoma and five years later suffered a mini-stroke.

As the former CEO of Carers WA for 12 years, Fynn was well equipped to care for a terminally ill partner. Yet she could do little to fix the pain and suffering that overtook Deverall in his final two years. The tall, athletic figure, a former Masters squash champion, changed as a cocktail of cancer drugs and assorted illnesses took a hold on his body. "Clive had so many things wrong that about the only specialist not involved was a cardiologist," says Fynn. "His leg went dead, his hands cramped badly, he lived with chronic headaches.

And they couldn't give reasons for any of this. He had a complex condition but didn't have a diagnosis that said, 'You will be terminal within a few months'.

The steroids he took caused mood swings, weight gain, failing eyesight and open wounds. "Yet they were the only thing that helped," Fynn says. "Despite the best medical care, he was in every kind of pain. He'd said to his doctors, 'I don't know how much longer I can go on like this'." In one of his referral letters, a doctor wrote: "This man is actively considering euthanasia."



Marieke Vervoort

When I caught up with him last September, Deverall told me he envied Belgian Paralympian wheelchair racer Marieke Vervoort, who had just won a medal in Rio. She had spoken openly about her incurable degenerative muscle disease and the option available in her native country to legally terminate her life. "When the moment comes," she told reporters, "when I have more bad days than good days, then I have my euthanasia papers, but the time is not there yet."

Deverall complained that it was a better option than the uncertainty he faced. He and a group of terminally ill friends discussed turning to the black market. "Three of them have purchased the drug Nembutal," he told me, referring to the veterinary barbiturate promoted by euthanasia advocate and Exit International founder Philip Nitschke. He seethed with frustration as he described his futile attempts to find a laboratory that would agree to test

samples of the drug, which is illegal to import or possess in Australia. “They just threaten to report [us] to the Australian Border Patrol and they refer to the \$825,000 fine,” he said.

At Christmas, he spoke to his family about ending his life. Says Fynn: “I knew he’d joined Exit and that he supported Dying with Dignity, that he’d tried to source Nembutal but he’d never use it unless he could get it tested.”

When his health permitted, he publicly defended Perth doctor Alida Lancee, who was investigated by police after she admitted providing a lethal injection to a patient in her 80s. Dying of emphysema, the woman had attempted suicide several times. When Lancee decided to stand against Premier Barnett in his safe Liberal seat of Cottesloe, Deverall turned up to support her.

Both of them worked on a private member’s bill with the Greens MP Robin Chapple to draw up end-of-life laws. Meanwhile, Deverall remained determined to attend a family wedding in the Bahamas in late May — if his lungs were unable to handle plane travel, he planned to book a passage on a freight ship. Two weeks before he died, he told his wife: “I don’t think I’m going to make it.” His new suit still hangs upstairs at home.

On March 11, WA’s election day, his wife gave him a kiss and a hug and went for a walk with a friend. “I said, ‘I’ll see you in a couple of hours.’ I had no inkling ... I was standing outside at 10.30 that morning when a police car turned into the road. I knew Clive’s pain was over.”



Deverall with his wife, Noreen Fynn.

Vicki Barry runs the Perth Death Cafe, which meets every couple of months. “It’s part of a global movement to encourage people to talk about death,” she says. Topics range from ‘Death over doughnuts’ to ‘The best death possible’. “I encourage people to bring a family member or friends who may not be comfortable talking about death and dying,” she says. “If you’re not having conversations with people around you, then when you become incapacitated they don’t know what you want. The conversations need to be around, ‘How do you die well?’”



Vicki Barry.

Barry had those conversations when her elderly mother had chronic heart disease and could barely walk. When doctors suggested amputating her mother’s legs to save her life, she said, “Can we just let nature take its course?” Her mother died soon afterwards. Her husband has been diagnosed with younger onset dementia; “We’ve got five to 10 good years, but we’ll make the most of them,” she says philosophically.

Yet Barry is not a fan of euthanasia legislation to “solve” the problem of difficult deaths. As an active supporter of Palliative Care WA, she believes it undermines the alternatives. “The sad thing about our medical system is that people end up not knowing much. It’s about being prepared. We’re all living longer but we’re actually dying longer too.” She says she read Andrew Denton’s compilation of end-of-life testimonies, called *The Damage Done*, in one sitting. “I felt some of the people clearly had no idea of the options available to them. All that talk of bad deaths can undermine some of the good work that palliative care does. We don’t hear enough about the good deaths.”

Barry finds it sad that Deverall, who did so much towards giving people a “good” death, lost faith that it could be delivered to him. Others say an urgent need for more palliative care resources is reflected in the fact that 70 per cent of Australians want to die at home but only 14 per cent do.

Denton has a different take on Deverall’s suicide. “When the former president of Palliative Care WA takes his life in a public place in order to end his irreversible suffering and to protect his family from the same, it could hardly be more significant,” he told the ABC. “It gives the lie to the line trotted out by politicians who oppose assisted dying laws, and their fellow travellers in the medical profession, that ‘palliative care can take care of everything’. It’s not true. Clive, who knew the realities better than anyone, because he was living and dying them, knew it was not true, too.”

Deverall came to that conclusion last October, announcing he no longer believed that palliative care was the answer for between four and eight per cent of patients, including him. “Certainly I still embrace what palliative care stands for,” he said in a TV interview, “but they avoid the elephant in the room, the end-stage patients [for whom] symptoms cannot be controlled.” As if presaging his own death, he said: “The lack of compassionate law in this state will force some people into taking their own lives in a fairly brutal way.”

It is precisely that thinking that may lead Victorian legislators to cast their vote in favour of assisted dying laws later this year. Denton — who is writing a book and was not available to be interviewed — is so convinced Victoria will get over the line that, for now, Go Gentle Australia’s activities are focused on that state alone.

Victoria’s advisory panel on assisted dying laws includes two high-profile palliative and -medical care experts who have become converts to the cause. Chair Brian Owler is a former head of the Australian Medical Association, which remains opposed to euthanasia. Roger Hunt is a palliative medicine specialist of three decades’ standing. A third high-profile convert, not on the panel, is Emeritus Professor Ian Maddocks, one of Australia’s top palliative care specialists and a former Senior Australian of the Year. Adelaide-based Maddocks favours physician-assisted dying which, “had it been available, would have made me a better palliative care physician”.

“I’m thinking of a number of patients for whom I have prescribed drugs to make sure they were comfortable through their final illness,” he told The Australian last September.

“[Patients] who suddenly died in secret by, I think, taking those drugs all together, and I didn’t know about it.”



Paul Russell

Paul Russell, the South Australian director of anti-euthanasia group Hope, says he’s not fussed by such high-profile converts. “There’s no question those three gentlemen have decided in favour of it. They are three among thousands.”

But it was the powerful testimony of Victoria’s coroner John Olle to a parliamentary committee into end-of-life choices that may linger in the minds of the state’s MPs when they vote later this year. Choking back tears, Olle described how 240 suicides across the state in four years were people violently ending their suffering due to an “irreversible decline” in health. Poisoning, hanging and shooting were the main methods, he told the 2015 inquiry. “It goes on and on,” he added.

In whatever state a euthanasia law emerges, it is likely to apply only to adults with a terminal illness who have six or 12 months to live. In Deverall’s home state, Greens MP Robin Chapple says his private members bill will follow Victoria’s careful balancing of rights with safeguards. “We know there’s between 80 and 90 per cent of West Australians who support forms of dignity in dying,” he says. But he stresses the bill would almost certainly exclude those with a mental illness, those under 18 and those who have not lived in the state for three years: “We don’t want ‘dignity with dying’ tourism.”

In the same week that Denton and Deverall were anticipating victory in the lead-up to South Australia’s assisted suicide bill, Perth-based activist Sam Connor was folding her wheelchair and flying to Adelaide to confront Denton and Go Gentle supporters. Connor uses humour to rise above the challenges of earning a living as an articulate disability advocate while raising six children. She and other women from four states, who dubbed

themselves the “Crip Army”, landed in Adelaide to make a very personal point. As South Australia’s initial draft bill was worded (it was later tightened), it would include people who were chronically ill or in pain, and was not restricted to terminally ill patients. The women felt that they fitted the category of people “allowed” to be euthanased.

As they left parliament, the Crip Army spied Denton on the steps giving a press conference. “Most of us are conflicted,” recalls Connor wryly, “Denton is a compassionate and talented comedian and interviewer, and we’re caught between helpless fan-girling and a rising and ironic desire to kill. I wheel up to him and he catches my eye from the corner of his. ‘Hello,’ I say. ‘You’re the guy who wants to kill us, right?’

“Denton doesn’t miss a beat,” she says. He invites them to meet up later, when he listens carefully to their side of the argument. “We talk about some issues he might not have considered. The fact that many of us are far cheaper to kill than to keep alive.”

Shayne Higson, from Dying With Dignity in NSW, says disability advocates should not be afraid. “People should not fear legislation that will — in every state — stipulate that the person must be terminally ill and likely to die within six to 12 months,” she insists. “If they look at the detail of the bill, it’s not for people with disability. It’s for people who are dying.”

Meanwhile, anti-euthanasia campaigner Paul Russell says 2017 must remain “a year for vigilance”. “Mr Denton and others will be talking things up and it’s their right to do that. But I remain quietly confident ... I think Andrew [Denton] once wryly asked me what it was like to be on the wrong side of history. I didn’t reply but in fact I don’t think I am.”

And what of the brutal final act of a man whose reputation Russell knew and respected, Clive Deverall? “I think it was incredibly sad,” he responds. “People ultimately do make their own decisions, but making a law that effectively endorses suicide is too dangerous.”

Lifeline 13 11 14

<http://www.theaustralian.com.au/life/weekend-australian-magazine/clive-deverall-andrew-denton-euthanasia-assisted-dying/news-story/30067c6a6dffa3a7a61c7de58c977a92>