

Better Off Dead

Transcript for season 2, Bonus Episode 14: Last Words: Voluntary Assisted Dying

Andrew Denton: Welcome to this bonus episode of Better Off Dead, a replay of Radio National's Big Ideas program, recorded in April 2021 at Melbourne's Wheeler Centre. It features former voluntary assisted dying conscientious objector, oncologist Dr Phillip Parente; Chair of the Assisted Dying Review Board, Justice Betty King; terminally ill Shepparton man Ron Poole; and myself in discussion, expertly moderated by Paul Barclay. It's a fascinating conversation, made all the more poignant by the knowledge that Ron, who died only a week later, chose to spend some of his final hours helping us understand what the choice offered by Victoria's law meant for him.

[BIG IDEAS THEME MUSIC]

Paul Barclay: This is Big Ideas. I'm Paul Barclay. In 2017, Victoria became the first state in Australia to enact legislation to allow those with an incurable illness to choose to hasten the end of their life. The law came into effect in June 2019, and since then, more than 220 Victorians have died as a result of accessing the law. As things currently stand, Victoria is the only state where voluntary assisted dying is an option for people with a terminal illness. Western Australia and Tasmania have passed similar laws, but they're yet to take effect. Other states are currently considering the issue and are likely to vote on it in the next year or so. But after two years of operation in Victoria, how are the laws working and where is the debate at?

This was the subject of a recent discussion at the Wheeler Centre, which brought together a panel of speakers. Andrew Denton is one of our most creative and talented TV broadcasters and producers. He's the founder of Go Gentle Australia and advocates for better end-of-life choices in Australia. He hosts the podcast Better Off Dead, which has just launched its second season. Justice Betty King QC is chairperson of the Voluntary Assisted Dying Review Board and a former Judge of the Supreme Court of Victoria. Associate Professor Phillip Parente is a medical oncologist and the Director of Cancer Services for Eastern Health. And our other speaker is Ron Poole. Ron has idiopathic pulmonary fibrosis and has elected to pursue voluntary assisted dying after receiving a prognosis of having less than six months to live.

Just a warning before we begin: this discussion deals with death and dying and people choosing to die in certain circumstances. If this conversation raises any issues for you, there are resources and support services available, including a 24/7 crisis support phone line from Lifeline. The number is 131 114. You can also find more information, links, and phone numbers on the Better Off Dead website.

[LIVE AUDIENCE APPLAUDS]

Paul Barclay: Phillip, I'll come to you first of all, being the only medical practitioner on our panel. How do you think the laws have been working? What would be your verdict on the first two years or so of people being able to access them?

Phillip Parente: I think the laws, initially, people accessing the legislation, was difficult. But as the information that was disseminated amongst the public became more evident, patients really came to us as doctors, and for me – medical oncologists – my cancer patients were asking about voluntary assisted dying. Initially, I think there were barriers which most hospitals encountered, but only because we didn't really implement the laws well, there was an implementation issue. But most hospitals took it on board. And patients have been able to access it in a very swift way and have

enabled Navigators, Voluntary Assisted Dying Navigators. They're the central Navigators. But most hospitals now have their own Navigator, where we contact these people to help patients navigate the many safeguards that we need to go through to access the medication. So, I think it's working well. It can always work better, in medicine we always can do things better. But it's becoming increasingly more of an option that I've seen. We're getting increasingly busier as well, as assisted dying assessors, and therefore that will always pose another issue with the legislation.

Paul Barclay: It's still a new thing, and we know that many in the medical establishment opposed these laws – still oppose these laws. How much of a problem is that, and does that continue to be?

Phillip Parente: Well, my speciality – medical oncology – is fractured because of it. I can tell you that now. We did a survey, and there's 50% really for and 50% opposed. We're split down the middle, and that was published. And good friends have probably become lesser good friends because of our views on voluntary assisted dying. It has really, I think, split our profession, our relationship with palliative care. People who are pro-voluntary assisted dying can't see the views of some palliative care physicians or institutions. So, there are new issues to address and to discuss and come to a common ground.

Paul Barclay: Andrew, you've spoken to so many people about this – people who have availed themselves of the law. What are your thoughts? Is it working well? Do enough people have access to the laws? What would be your view?

Andrew Denton: Well, if you go by the frame of the parliamentary debate, and the claims that were made about the terrible things that would happen once a law like this came in, yes, it's working very well. Absolutely none of the things that were suggested would happen – that the safeguards wouldn't work, that people will be coerced, that it would be easy to access – have turned out to be true. So, in that regard, it's working really well. And also in a historical regard, in that before the Victorian Parliament made this choice, made this decision, the gifts of choice and the gifts of release available to terminally ill people were not available in any state in Australia. So, that's a huge step forward. And this is a long conversation and will continue about end-of-life care, right across the medical community and the community at large. So, this was a really, really important step that has changed the conversation, not just here, but in Australia.

In terms of access – and Phillip's spoken to it, and Betty, I'm sure, will speak to this more – the law is written deliberately very conservatively. We have some of the MPs here tonight that were responsible for passing the law. And they would remember well why the – I think it was touted as the most conservative law of its kind in the world, with 68 safeguards – that was necessary politically for it to do so. But the result has been not just because of the law, but because of what Phillip talked about, which is that many doctors have been reluctant to get involved, or strongly disagree, so that there still aren't a lot of doctors who are accredited to assess people for assisted dying. But the result has been that it hasn't – and Ron will talk to this, too – it is a very difficult law to access. And for some people, it's been prohibitively difficult, and I think it is indicative of, that is, to this point, based on Betty's last report, almost a third of the people that legally get this medication, so they have the necessary illness and they pass all the qualifications, they are – it's voluntary, they're mentally competent, all those hoops they've gone through – they actually die before they get the medication.

Now partly that's because people come to this very late, and why is that? Because news flash, we don't want to die. But a lot of that is because it's not easy. And I, in small ways, Tasmania and Western Australia have passed a law based on Victoria, they have tried to make some areas easier. The law here is due for review. And I think it's three years' time and look, those who oppose these

laws suggest that any change to it is an example of a slippery slope. But I would hope – and a sensible Parliament, as it would with any law – if it's looking at who is this law designed for, people who are terminally and seriously ill, and if the functioning of the law makes it more difficult for those people to be helped when they most need that help, then maybe there are things that can and should be changed.

Paul Barclay: Mmm. So, Betty, you're on the board that's overseeing this terribly important job. What would you say needs to be improved? What recommendations, if any, would you make to fine tune?

Betty King: We're about three years away from making the recommendations, so I really can't say precisely what they will be, but we'll be looking at access as being one of the major issues. Is it more appropriate for people to actually be informed about this being a process available to them? At the moment, doctors cannot tell patients that voluntary assisted dying is available. Western Australia has drawn their legislation and they have said that doctors can, so we will look at how it goes in Western Australia and see if that's an improvement that could help Victoria, for example. There's lots of different things. People come to this often, as Andrew says, late, and they come late because they really just haven't known about it, haven't been told about it, or are in a situation of ... they don't want to face mortality. And then when they do come and they're very sick, by that stage, it's very hard for them to access the doctors, and they have to travel. They have to go to the doctors. Doctors can't use Telehealth because of Commonwealth legislation. So, there's a lot of impediments that weren't intended that I think we'll be looking at and trying to find answers for.

Paul Barclay: So, Ron, I just wanted to get a bit of the background of that before I came to you. And perhaps you can tell us a little bit about your story, your terminal condition – if you don't mind talking about it – and why you've chosen to pursue voluntary assisted dying for yourself.

Ron Poole: There was – there's been a few points raised. And I think the biggest one is that not enough people know about the scheme. As you said, it's too late for some people because they haven't heard about it. So, I think it needs to be out there a bit more for people to know. I was diagnosed in October 2018 with my condition, and I had a very good talk with my physician about it, and then I talked to my GP, and I knew this program was in place. So, this is back in '18. And so, I went online, and I found out about assisted dying then, so I knew what all the ramifications were and everything. And I was lucky that my two doctors agreed with me. So, when my physician said to me, 'You've come into the six-month window, you can go ahead and apply for the assisted dying.' So that's what I did.

And I had to get to a... I had to have two independent doctors assess me, which was two hours at a time. And then after they'd said, 'Yes, you've passed all the marks,' then the pharmacist came up with a little box. And they went through a two-hour process and said, 'Yes, you're alright.' So, sitting at home, I have my little black box. Whether I use it or not is my choice. The box is there.

Paul Barclay: The box is there now?

Ron Poole: The box is in there for me to use at any time. And how I use it or if I use it is entirely my choice. And I think this is the thing, as you said: people don't know about it. If you leave it too late, you're not going to pass those hurdles of those independent doctors' inquiries. And I think that's the most important thing for people, to be aware of it, where they do get sick, terminally sick, because if I don't have assisted dying, I'm going to die a very painful death. Now, I don't want that. So, this is a way for me to go, and a way for other people to go. It's because if the illness is going to kill you, it can be a very terrible death, as Andrew knows with his own father. Right? He would not like anyone else to go through the same thing. Is that right? So, so, that's what it's all about.

Paul Barclay: Phillip, just – sorry, just bearing in mind what Ron was saying there, and the consultation with the two doctors. Obviously, one needs to be thorough about matters like this. How well, though, is that working? How easy or difficult is it to get the doctors to give the prognosis that then allows the patient to pursue voluntary assisted dying?

Phillip Parente: So, I'm a medical oncologist. So, when it comes to non-cancer conditions, I can't comment. I think it's quite easy, clinically, to pick up prognosis less than six months in a cancer patient. We have all our scientific evidence, doctors' gut feeling, we've got... I've got 30 years' experience. We know. So that's not an issue, I don't think, picking prognosis. And obviously, I've assessed patients who have not been eligible on that criteria. But I've said, 'Look, not today. But please ask me again. Or I will let you know, because now you've asked for it again, I can open the discussion.'

But my biggest issue is what has been echoed in this panel. It's really the discussion with the patients, that's the major inhibition. The foundation of a good doctor-patient relationship is enabling the patient to have all the information in front of them to make an informed decision. Inhibiting us giving them this option, I think, inhibits especially marginalised groups. You had to have good access to internet or good access to social media, or a good grasp of the English language to know that this is around, and a lot of patients don't. And when I discuss with patients – you know, third line chemotherapy or palliative care, we do nothing, and we keep you comfortable – it doesn't sit well with me that I can't introduce voluntary assisted dying as an option. It may not be, they may dismiss it. But that's why we, when I write things down – I always write things down for my patients, and I have arrows – it's... it doesn't sit well with me that that's not an arrow when I know that it's legally available, but I'm inhibited from speaking about it. So, I think that's a major issue. And it would be nice to see how the Western Australian colleagues will tackle that, because I think it will be tackled quite nicely and we can learn from them.

Paul Barclay: And Betty, do we have enough medically trained practitioners working in this field at the moment?

Betty King: No, no, we don't. We... that's a matter for the medical practitioners. All we can do is encourage people. But as Phillip said, there is a schism in terms, I think, particularly of the more senior clinicians. I think that schism will dissipate as younger people come on, become qualified. They seem to be much more... they're taught ethics, they're taught a range of things at medical school now that they probably weren't taught when the senior clinicians were being trained. And I think that will alleviate. It seems to be pretty universal, that there's slow – around the world – slow uptake in terms of clinicians, but it just continues and it has with Victoria.

Our problem is regionally. We're short of doctors anyway, regionally. So, when you divide the doctors with that sort of schism, you have a problem in terms of access for those in regional areas. And also, I mean, one of the things is it takes a lot of time, as we just heard. Two hours to do an assessment. It is not paid for. There is no funding for it. In terms of, you know, this is not something that our doctor can charge for via government funding. Victoria does make available funds to compensate, if necessary, because people – if you take someone like a neurologist who needs to see someone for neurodegenerative disease, the neurologist is based in Melbourne, the patient is in Mildura. And they've got to get to the patient, or the patient's got to get to them. So, you can talk about a complete day of someone, of a doctor's practice, gone.

Paul Barclay: And importantly, there's no access to Telehealth, either. My understanding is this is a federal restriction. That this is something the states can't overrule. It requires federal law.

Betty King: It's federal law. And it was brought in because of, I think, basically, Phillip Nitschke and chat rooms, was how the description was in the Parliament. You know, chat rooms advocating people go and kill themselves. This is not what we're talking about here. This is the will of the people. It has been voted for in our parliament. It has been adopted. The Commonwealth could do this incredibly easily by just saying, 'Legally applied voluntary assisted dying is not suicide, end of story.' And then Telehealth could be used. But they won't.

Phillip Parente: In saying that, I think if it was enabled, I think Telehealth would be good in the regional areas, but I would feel uncomfortable discussing such an important treatment avenue over the phone. I would find it difficult, and I think most assessors would. The first assessment of the first consultation face-to-face, and then Telehealth for the subsequent ones where you're really just confirming, but all Telehealth? It just wouldn't sit well with me.

Andrew Denton: Yeah, and I'd agree with that. I think it's – Telehealth is for situations where it's very extreme. I've got one of the people I spoke to in the podcast. Her mum was 82, neurodegenerative disease, an agonising two-and-a-half-hour trip to go and see a specialist and then back, because she lived in regional Victoria and it would have taken two weeks for somebody to come, and every day was fearful for her. So, I think that's a clear situation where you'd use Telehealth. But a lot of the doctors I've spoken to would prefer face-to-face and I think that's appropriate. And I think that's where you have a law where it can be something like, 'Telehealth can be accessed where the situation demands it,' not as a default position.

Western Australia, of course, is a very big state, which is why their law does allow for Telehealth. It'll be a very interesting question to see if the Commonwealth tries to come down on that. Easy for me to say because it's not my court case, but I'd like to see that court case run because I would like to see this resolved once and for all. Essentially the federal government's – still – insistence that they're not going to change this law is the last rump of Kevin Andrews and the Howard government's religiously led overturning of the Northern Territory law back in '96, '97, which still disenfranchises almost 700,000 Australians' Parliaments from discussing this issue.

Paul Barclay: We're talking about voluntary assisted dying. This discussion took place at the Wheeler Centre and features Andrew Denton, Betty King, Ron Poole, and Phillip Parente.

I mean, we're talking really about, in a way, learning from the legislation that's been passed, perhaps fine-tuning it, perhaps looking at what can be improved, but the reality is we now have Victoria, Western Australia, Tasmania, with legislation. Queensland, with a unicameral Parliament with only one House of Parliament to get through, and with a government that seems inclined in that direction, looks like it will probably pass euthanasia legislation. So, Andrew, there is movement on this now – significant movement. Is this debate over and done with now, or is it just, you know, lock it away, and it's like, you know, with this sweeping through the country, you can go back to making your TV programs, and can your previous life resume itself now?

Andrew Denton: The endless quest for the Logie that defines my life. *[AUDIENCE LAUGHS]* Yes. It's a dream, Paul. No, look, I think politically it's so far from over. As I said, the Territories don't even have the right to debate this in their Parliaments. Hard to believe, but true in Australia. The South Australian Parliament is about to debate this in their Upper House for the 17th time. And my understanding of the numbers in the Upper House right now is it's extremely tight. So, it may well go down for the 17th time. The New South Wales Parliament has just welcomed to its Upper House, in a balance of our position, Lyle Shelton from the Australian Christian lobby. I'll just go, 'Dot, dot, dot,' because you can imagine how that's going to go. It's a very hard argument. And it's not helped by the

fact – and Phillip’s referred to this – it is often the medical community that has led – and to my eyes, in many cases misinformed – this debate in an attempt to defend what they believe is the appropriate status quo, and certainly, in contradiction to the vast majority of their patients who want something better and better choices. So, I don't think it's over.

However, even if this law is passed around Australia, the passing of this law doesn't address broader questions in end-of-life care, which aren't even necessarily to do with this law. It's partly to do with the public educating itself about advanced care directives and what it needs, and planning for the end of life. And by the way, I still haven't done my Advance Care Directive because I'm not going to die. *[PAUL AND AUDIENCE CHUCKLE]* But it also, I think, within the medical community, what I've discerned – and Phillip, you may agree or disagree – is there's still, there was an interesting survey done of doctors in Queensland a couple of years ago. And I think it was something... it was over 70% of doctors polled admitted to having given what they will consider to be futile care at the end of life. And, anecdotally, the reasons doctors gave included, 'It's easier to do that than to have the hard conversation.' So, I think there are broader conversations to be had within the medical community about end-of-life care and how it's conducted. And that's not strictly to do with this law.

Paul Barclay: I mean, look, these are hard issues. Phillip, you're a Catholic who long objected.

Phillip Parente: Still am a Catholic. *[CHUCKLES. AUDIENCE LAUGHS]*

Paul Barclay: You haven't bailed on Catholicism as a result of changing your mind on voluntary assisted dying?

Andrew Denton: By the way, God will be the judge if you're still a Catholic.

[AUDIENCE LAUGHS]

Phillip Parente: I totally agree.

Paul Barclay: So, what led you to change your mind?

Phillip Parente: So, look, I will own it: I was an opposer. I even signed the letter to Parliament, my name will be ever on there, and I will own it. And it was probably just my Catholic upbringing, you know, sanctity of life, you know, against abortion, against euthanasia, the polarised views. You know, The Catholic Church has really taught that us since I was in grade prep to Year 12. So, it was just a natural assumption that I would, you know, that I would oppose it. But I never thought about the other view – the patient-centred view – and when the legislation was enacted, and I had my first patient come to me, it challenged my own, you know, my own ethics. Here I am, I'm really the patient's advocate. And I have to treat them fairly, without any prejudice, and enable them to have lawful treatment. And by staying a conscientious objector just didn't sit well with me.

You know, I pride myself in holistic care, that I'm here at the beginning of their diagnosis and at the end, and at their most important time. This is not an easy decision. People think that going through voluntary assisted dying is a simple decision. It is not. They have agonised it; I've seen it. They've agonised it within themselves, then they've agonised it with their loved ones, and by the time they come to me, I can see the... the conflict they've had, and I can't see myself as being potentially Godlike and saying, 'No, I'm not doing that.' If they meet the eligibility criteria, there's many safeguards that are present, then I will enable that. It's their choice. And they may take the medication, or they may not. But my role is really to be their advocate.

Paul Barclay: And Ron, what's been the response of your friends, your extended family to the decision that you've taken?

Ron Poole: They all were aware that it's been a long-held belief of mine. Because I was a farmer many years ago, and had many animals. And of course, when you've got animals, when they're sick, what do you do? You put them down. And I've always said, with people who are really sick, 'Why shouldn't they have the right, the choice to do that themselves?' And they talked about palliative care. Yes, you can help people a long way, but there's a degree, like myself, where all the palliative care in the world is not going to help me. And when my... when my doctor said to me, when we had a good talk, I said, 'Well, what's the bottom line?' He said, 'You will get to that stage where you can no longer breathe for yourself, we'll put you in a hospital on a machine.' 'Well,' I said, 'there's no way I'm going on a machine.' And I was lucky enough to be living in Victoria and be able to access assisted dying.

As I said, I've got it sitting at home. I've gone downhill lately, and I'm looking at three or four weeks myself before I do go. That's... I'm fully aware of it. I'm not scared of it. And I've also got the choice; I don't have to use it. And that is a choice of anyone who goes on the scheme. They may get through all the hurdles, but not everyone will use it because through circumstances, or ideals or whatever, they have a change of mind, and that's one of the good things about it. But I still think that not enough people know about it. I think that's one of the biggest problems, we're talking about it, but there's a lot of people outside who don't know that the scheme is available. And, as it was said, some people leave it too late, and they can't access it. Because you've got to have a mental facility to be able to explain to the doctors that what you want is end of life. Now, if you've gone past that stage where you can't discuss that in a forthright way, you will not pass the barriers, and you'll get passed over. So, all the... I think everything is in place to make it safe, I think it is a safe structure, and the hurdles are there to jump and if you can't jump them, you won't get it.

Paul Barclay: What would happen, Betty, if a medical practitioner confronted with somebody like Ron, who didn't know that this was available, did actually suggest in a consultation that, well, this is an option? What... are there penalties for practitioners?

Betty King: Yes, it's an offence under the Act. It's actually an offence, a criminal offence.

Phillip Parente: And an AHPRA notification.

Ron Poole: The doctors are hamstrung in many ways.

Betty King: Indeed. And one of the biggest problems in respect to that is people who don't have English as their first language, people who don't... who are old, don't know about the internet, don't know how to access things. You know, even well-educated people do not know where to start. I've had friends just call me and say, 'Look, you know, I need some help,' and I just say, 'Care Navigators.' But that could normally be, you'd think, be found on the internet, but they just don't know where to start. And as for those who are not well educated, I don't know how they're going to get that information.

Ron Poole: That's right. It wasn't easy finding out the initial, like, how to do it, and I went online. And Mr Google took a while before he gave me the right answers. [AUDIENCE LAUGHS] But he did in the end, and the assisted dying program, I contacted them and that's how the wheel started. But as I said before, and I know that the Assisted Dying program by law are not allowed to advertise. So, it's only through podcasts like this, and other ways, can we promote it. So people become aware of what it's all about. And I think this is where the issue has to be to promote it, so people are aware of it.

Andrew Denton: There's also, Victoria has a really excellent organisation – Dying with Dignity Victoria – who long advocated for this law and are acting in an unofficial capacity, as ombudsman about it. And they're also there to provide information and advice.

Paul Barclay: Ron mentioned, before, palliative care. And one of the things that strikes me about this debate – and it is still a debate, and there are critics out there, still, presumably attempting to overturn these laws and make sure that other jurisdictions don't pass them. Doctors and palliative care specialists will say that there is effective pain killing medication that alleviates suffering for everyone. So that's the – their point is, this law is not needed because this medicine can work for everyone. You've spoken to people – I've heard your discussions with people on your podcast – who tell the most terrible stories, distressing stories of suffering. How do we square these two different versions? These two different realities?

Andrew Denton: It's probably what I most struggle with in this debate. When I hear doctors – and sometimes they're senior doctors – make that claim, I feel, 'Surely they know that that is not true.' I mean, put aside the fact that Palliative Care Australia says it's not true. Put aside the fact that their own research shows it isn't true. Put aside the senior palliative care doctors and nurses that have stepped forward and given evidence to parliamentary inquiries, which is accepted, to say that's not true. Just take the people, like Ron, that I've spoken to over the course of simply this podcast. You know, you talk about someone like Phil Ferrarotto, 70. He had a genetic predisposition to cancer, you name an organ, Phil, over 18 years, had it taken out. By the end – he still called himself Lucky Phil – by the end, his daughter described him as looking like a medical experiment, and every breath was agony, and he was on a fentanyl drip. Wasn't touching the sides. Palliative Care, for all its benefits, can't help Phil.

Young Alex Blain, 28 years old, 19 rounds of chemotherapy, 19, with Ewing sarcoma, and at the end, he said, 'I had given my body over to medical science. Voluntary assisted dying gave me my life back.' And his last words were, 'Fuck cancer,' as he died. Palliative care can't help Alex Blain. Ron, who I spoke to, Fiona McClure, who is sitting there right now with this medication out in Heathcote, who has metastatic cancer throughout her body, who saw her husband, over ten painful days, die – despite the best of palliative care – in a horrible way. Not only does she not want to risk that experience, she knows what the cancer's going to do to her. It's not just about – it's certainly not just about pain; it's about that totality of suffering. The way I describe it is, 'Think of everything that makes you, you. Then imagine it being stripped away one by one, and knowing it's going to continue for the rest of your life. It's not going to get better.' It's about being able to have some control over that. Not – with due respect to Phillip and every other medical practitioner – to have them having the say over it. And I do think that those doctors that make this claim, I wonder if they have – and I wish they would – sit down with the families of the people that have used this law and sit down with the people who have this medication. And maybe they would have a very different understanding of what palliative care can do, and what it means to some of the people that choose this law.

Paul Barclay: I mean, palliative care is tremendously important. And we wouldn't want to diminish that. And I wonder, Phillip, whether – in part – that explains the refusal to acknowledge that palliative care does not work for all end of life terminal cases. If not that, how do you possibly explain the fact that there are people who persist with this argument that it will alleviate suffering for everybody?

Phillip Parente: That's a tough question. So, you know, I would say that that resistance, it really does come from a few of the palliative care physicians – not all, but a few of them. I would say, quite a lot of them. And the way that I see it – I haven't spoken to them about it, but the way that I see it – by

validating voluntary assisted dying, they may see it as a way that they've failed the patient. It's – that's how I see it. They don't want to acknowledge that it's – it really invalidates palliative care, which I don't think that's the case. Palliative care is just as important. And a lot of patients who undergo voluntary assisted dying have had excellent palliative care. But they're at a different stage of their illness.

Betty King: Can I just add that almost 100% of the patients – of the people who use voluntary assisted dying are still involved with the palliative care service? Right? They don't need to be separate. It's all part of an end-of-life process. And most palliative care organisations are helpful to the person.

Ron Poole: Yeah, well, I've got to say that in Shepparton, where I am, I've been getting very good support from hospice, from other people. It isn't like I've been left alone, even though they know I'm on that program. Even though it's not their way of going, but they will stay with me, and I've got a doctor who will be with me when that happens. So palliative care is good. I'm not saying, you know, it should be done away with. But palliative care isn't going to answer the question for a lot of people.

Andrew Denton: And this comes back to what I was saying earlier. This whole conversation is about better end-of-life care for everyone, which includes palliative care. Since this law was introduced, this government has added another \$130 million to palliative care. Queensland, as part of the debate that they're about to have about assisted dying, have put \$170 million into palliative care for the next six years. It's not an either/or, and neither should it be. And, you know, I think we're, we've perhaps neatly stepped around the small elephant in the room here, which is that the roots of palliative care are strongly Christian roots, and in a very beautiful way, I might add. And that there is a view within elements of strongly Christian care that a natural death – in other words, not a hastened death – that that dying process is a time of spiritual growth. And it's very important, and to hasten death is not only to remove that time. They use much harsher language, which is, 'It's to abandon people and it's not to show them love,' which I strongly object to. But there's also the belief that this is... that death is about God's victory over death, and to take this away is a terrible thing to do. Now, they are entirely valid beliefs; I don't criticise them. But unfortunately, in states where this law doesn't exist, those beliefs are still allowed to prevail in the clinical environment, because there is no great regulation of the amounts of medication given at the end of life. It's really up to what a doctor thinks is right.

Paul Barclay: Yeah, I mean, there's no getting away from the fact, either, Betty, that voluntary assisted dying permits the state to authorise somebody's desire to end their life under certain circumstances. This leads some critics to say that this is essentially state-sanctioned killing. Without the state passing this law, this would not be permissible. What would your response to that type of language be?

Betty King: *[SIGHS]* My response to it would be that people were doing... killing themselves anyway. They were using shotguns in back sheds; they were hanging themselves from rafters.

Ron Poole: Excuse me, that's the thing that's always got to me, is if you haven't got this, people look at suicide, and some terrible deaths in suicide.

Betty King: People, families, family members come home and find them. And the whole process is so traumatic. Just look at the Coroner's report in respect to this. And it stopped. We're not having that anymore. I just, I don't understand why people don't get this part. It's voluntary.

Phillip Parente: There's also evidence that we've just regulated something that was happening in an unregulated fashion within the medical profession. Having it regulated, the safeguards, it actually protects both patients and the vulnerable, and doctors alike. We're all protected with the legislation. It did happen in unregulated practice; the evidence is there, not just in Australia, but worldwide. Validating it via a law has protected all.

Andrew Denton: And I would add that it is a quite carefully planted misunderstanding, that we don't have laws to assist people to die before this one. We do. You can legally refuse all medication; you can legally refuse – ah – stop eating and drinking. You will be given care, comfort care, as you die. But it is surely going to lead to your death. But it is slow. It is psychologically painful. It is often cruel. We already have a law to assist people to die – that one still exists. So, it is wrong to think that voluntary assisted dying suddenly dramatically shifted the game. What it did is take what was already understood in law and it made it far more humane, and it gave a far greater degree of control to the person who is dying.

Paul Barclay: Andrew Denton, Betty King, Ron Poole, and Phillip Parente are discussing voluntary assisted dying, in particular how the law is operating in Victoria. We're at the Wheeler Centre.

Dare I say, if I asked members of the audience to think of the disease that they would least like to get, I would imagine many people in the audience would think of dementia as being the condition that they most feared. There's lots of nodding going on at the stage here. I think we can all relate to that. Can voluntary assisted dying ever be applied to end-stage dementia, given that people who have end-stage dementia long ago lost the ability to consent to it? Andrew.

Andrew Denton: Hardest part of the question, the one I get asked most often. Like, I would imagine, most people in this room, I've certainly seen what dementia can do in my extended family. I'll answer by talking about what I saw: two things. First of all, the core of this law in Australia is that it's voluntary, and you have to be mentally competent. So, it doesn't apply. In the Netherlands, which has the longest conversation about this anywhere in the world, they have an entirely different way of thinking about it, which is unbearable and untreatable suffering. And they have a clinical – the life-ending clinic, which deals with what they call 'specialised cases.' And that can include dementia. And I spent some time with the man who runs that clinic, and then with a family whose... the daughter of a woman who had had dementia, who had accessed the euthanasia laws. And even though they didn't know I was talking to each of them, when I put their two stories together, I realised I had one story, which was, 'Yes, it is possible, in rare circumstances, in the Netherlands to access that law, but you still have to prove you're mentally competent.' So, this woman had to go through incredible hoops. And the night before, her daughter, who still wasn't sure, heard the nurse say to her, 'Tomorrow is the day. Do you want to drink? Or do you want to be injected?' And she heard her mother say, 'Of course I want to drink. I'm always in charge of what I do.' And she knew then this is what her mother wanted.

But what the head of the life-ending clinic said was, 'People in this situation have to make a choice. They have to make the choice to leave the ball before midnight.' In other words, they have to choose to end their lives before it would naturally happen, or they have to drift off into the grey. So, I think it is a very difficult question. I don't think it's going to go away. I'm unsure about the idea of using Advance Care Directives for dementia and Alzheimer's, and this certainly makes me not popular amongst people on my side of the ledger, and I'm unsure about it because I think that you are then asking your doctor to act on something where they can't be sure that this is what the person wants. And I'm not sure that is a fair or right thing to do. But because it is such a huge medical issue in our

society... I think it's – is it the number one killer of Australians over 80? – it's not going to go away. And I think our society and all societies will be grappling with this.

Paul Barclay: I mean, for the purposes of defining dementia, so does it begin...? Because clearly, you can't consent when you're in late-stage dementia, so you'd need to be of sound mind, which would mean that you're in early stage dementia, when your quality of life can be quite good. In some cases, for a number of years.

Ron Poole: Yeah, well, that's the thing about those kinds of conditions. They're not medically sick, medically. I mean, mentally, they are. I've got no, nothing about that. But they're not medically sick such as myself. Their dementia is not going to kill them.

Andrew Denton: Well, it will, but over a long period of time.

Ron Poole: Oh, yes, I know, but it's, it's in a different stage altogether. And as, I mean, we've got the first stage though, of the assisted dying. Now, whether that can include other things like dementia later on is going to be a subject to be debated over many years, I'm sure. Whether that comes in, I don't know. But at the moment, as they said, you've got to go through the hoops. And if you can't answer all the questions to the doctors as to why you want to die, you won't get onto the program.

Paul Barclay: It would be very hard to imagine it being applied to dementia. Would you agree, Betty?

Betty King: I think it would be enormously hard, simply because there is no – one of the things you have to have is a diagnosis and a prognosis, and the prognosis currently is six months as a maximum, or up to 12 months if it's a neurodegenerative such as MND – so I just don't see how a doctor or a clinician of any type could come in and say, 'Well, yes, dementia is certainly, ultimately fatal.' But they, the prognosis, by the time they could give a prognosis of less than six months, or even less than 12 months, the person wouldn't be in a position to actually be able to say what they wanted. And I mean, I think the real thing is that this is to help the person. Not to help their family watching them suffer, [No.] but to help them. And so, it's got to be something that they can articulate: 'This is what I want.'

Paul Barclay: Well, they do articulate it, in many instances, beforehand. I mean, I'll say it right now: I would prefer to die than experience late-stage dementia. I can say it, it's now on the record, how that gets applied. And I know, I mean, part of getting voluntary assisted dying through in Victoria has been the safeguards have been very important at legitimising this legislation, and how you could mesh safeguards with voluntary assisted dying in terms of late-stage dementia is problematic.

Phillip, I just wanted to tell the story of a friend of mine who wrote an article about this late last year, about the quandary of dementia and voluntary assisted dying. His mother had dementia, and on many occasions, when he went to visit her, she would insist that he end her life. This happened a number of times, incredibly distressing for both of them. And he was writing about this, but then he wrote about an occasion when his mother had an infection, and the hospital rang him up and asked him, they said, 'Your mother's got an infection. What would you like us to do about it?' And he said, 'Well, is the infection treatable?' And they said, 'Yes, infection is treatable with antibiotics.' 'What's the chance of success?' 'Oh, the chance of success is fine.' And so he did what people would do in that situation and said, 'We'll treat her with the antibiotics.' It was only later on that he realised that they were opening the door for him. Nothing explicit was said, because I assume that would not be ethical. Does this sort of thing happen often?

Phillip Parente: Yes. So, when you assess someone's treatment pathway, you balance it against their quality of life – and we're not judgmental, we try not to be in the medical profession – but we speak

to the patient and the family members, and ask, 'Do you want treatment?' Now, Andrew said quite eloquently that doctors shy away from discussing the, you know, 'Do you want to treat or don't you want to treat?' In all my lectures, I always say, 'It's harder not to treat than to treat.' The easy pathway is to write the antibiotics and walk away and you know that antibiotics will fix it. The harder question, the real doctor will say, 'Your loved one has been in a nursing home for eight years, they've become bedbound, their quality of life is poor. How do you see it? Nature's way is, they've got an infection; just because we've got the antibiotics, it doesn't necessarily mean we have to give them. What would you like us to do?' It's shared decision-making. And the law allows us to withhold that treatment. I've got personal experience, my father had dementia, and a sort of every proud Italian man, did not recognise his children or his grandchildren. And when he had a stroke in the nursing home, we were given that same question, 'Let's take him to hospital, looks like he's got pneumonia,' but we elected to keep at the nursing home with the nurses that he loved, that he knew for the last three or four years of his life, and had palliative care there and let nature take its course. There's nature and then there's active treatment, and you know what's right within yourself.

Andrew Denton: Phillip's raised a really crucial point, which is that the third part of this conversation, there's doctors, there's the person in the bed, and then there's their family. And one of the palliative care doctors, one of the pioneers of palliative care in Australia, who I've spoken to many times over the last few years, told me a patient of his, a woman who is in her nineties who was clearly dying, and the son wanted her to have an operation because he couldn't accept the thought that she might die. So, 'Please, do something more, do something more.' And this is the other part of the question, which is, you know – Betty talks about this. The fears of coercion happening under Victorian law have proven not to be true, except in one way there is coercion, and it's the other way. It's coercion from families: 'Don't do this.' It's coercion from doctors: 'You shouldn't do this.' It's coercion from some institutions: 'We're going to discourage you from doing this or, in a few instances, block you.' The family's part in this conversation is a very big part of it, and in the assisted dying debate, there is an attempt – and you see it play out in parliaments – to make out that assisted dying is like some bright shining line, that we never did this, now we are doing this. There is no bright shining line in end-of-life care. There are the sorts of things that Phillip's talking about happening in families, in hospitals, in medical clinics around Australia every day of every week, and they're not easy. And it doesn't matter what law you write, there's always going to be grey.

Paul Barclay: Yeah, that stands in contrast, doesn't it, Betty, to the, kind of the cliché, if you like, the stereotype of the kids who are pushing the parents toward an early death so they can get hold of the inheritance.

Betty King: The house.

Phillip Parente: Like, I hear this all the time. It's not there. If anything, I see the loved ones, they're conflicted, you know. They're supporting their loved one, but they're not happy about it, either. So, I see the conflict. It's – I've never seen coercion.

Andrew Denton: Jill Hennessy – I'm not sure Jill's here tonight, but she's one of the people responsible for this law passing – responded to that scenario of using this law to coerce someone to die to get your hands on the house. She said, 'It would be harder than Ocean's 11, to use this law to do that.' And it's true. If you wanted to do that, you wouldn't use a law which is the most scrutinised area of medical practice to do it.

Betty King: Can I say that what we get, in terms of feedback from the contact person – which is often a child of the... a child or a sibling. And they refer to the fact that, you know, they didn't really want

their parent or their sibling to do this, but they agreed to support them on the basis of that was what the person wanted. And by the end of it, they talk about the fact that it was just a wonderful experience, in terms of it was with grace and dignity and smiles on faces. And people who really aren't supportive to begin with often end up supportive if they've travelled on that journey with that person.

Paul Barclay: Have you thought about this, Ron, about the moment? And what that will involve, who will be around you and so on?

Ron Poole: It's still a bit of a conflict, whether I do it by myself just with the doctor, or whether I have family and friends around. I really haven't made a decision. Is it fair on other people to watch you pass away, or not? Because the mixture you get, you got 30mL of it you have to swallow. And within four minutes, you go to sleep. After you go to sleep, it could be half an hour or more before you actually pass away. Now, do you want people there when that happens? Or would you rather them come in the room afterwards? And it's something I haven't made up my mind which way I'm going to go. I've got no problems with taking it. I'm not afraid of it. I'm not frightened. And it's something I've looked – I haven't looked forward to, of course. [CHUCKLES] But it's something I knew was gonna happen one way or the other. And this is a good way for me. I've got a choice and I've got an option. I've still got that option that I may not take it. That's my choice. And I think this is the other good thing about the assisted dying program. Everyone has got that choice, and choice for the end of life should be something that everyone should have.

Paul Barclay: You hear some beautiful stories that you relay on your podcast, Andrew, of the end. Perhaps you could share one of those stories, if you can recall the details?

Andrew Denton: I'll do this as quickly as I can. I made these two podcasts five years apart, and the first one I made was before this law existed, and I sat and spent quite a lot of time with – and I think some of his family members are here tonight – palliative care knows Ray Godbold, known as Velvet Ray for his gentle way with the dying. He had cancer. He didn't want to die in palliative care because he'd seen what the end could be like for his particular cancer. He had an illegal drug called nembatal, which he could drink when the time was right for him. But, like most people, Ray clung to life. He didn't want to farewell his family and it – because it's hard to do that, it's really hard to do it. And he hung on, and he hung on, and he hung on, until it was too late, even though he knew what would happen. And the description of his family of his last hours – his wife, who's a nurse, said, 'I've never seen anyone more distressed.' His older daughter, Ella, I can still hear her saying, 'I will never forget the look on his face, ever.'

Five years later, I talked to this man, Phil, who I mentioned before – Lucky Phil. Cancer also, like Ray. He couldn't swallow. So, he could be injected by a doctor, another oncologist, and his last moments with his family, his daughter, and his wife on either side, stroking his arm. There was laughter, and Phil's last words to his family were, 'Be happy.' And his death was peaceful. And I contrast those two, and it's the clearest way I can explain to somebody what the absence of the law means and what the need for the law is.

Paul Barclay: And that's where we'll have to leave our discussion on voluntary assisted dying. It was organised by the Wheeler Centre. Our speakers were Andrew Denton, Betty King, Ron Poole, and Phillip Parente. Their details can be found on the Big Ideas website.

A special thanks to Ron Poole, who, as you heard, had deeply-held beliefs about voluntary assisted dying. Sadly, Ron died on the evening of April the 26th, less than a week after this discussion took

place. Our thoughts are with his loved ones. Ron also features in Andrew Denton's podcast, Better Off Dead. You can listen to it on the Wheeler Centre website. We'll put a link on our homepage.

If this conversation has raised any issues for you, there are many resources and support services available, including a 24/7 crisis support phone line from Lifeline, 131 114.

That's it for today. I'm Paul Barclay. Thanks for listening. Until next time, bye for now.