Better Off Dead

Transcript for season 2, episode 7: The C Word

DISCLAIMER: This program is not about suicide. If you, or someone you know, needs immediate assistance with suicidal ideation or depression, please contact your 24/7 crisis support service. If you're in Australia, try Lifeline on 13 11 14, Kids Helpline on 1800 55 1800, or the other support services listed on our website at wheelercentre.com/betteroffdead.

For legal reasons, the words of Parliamentarians spoken in this episode are being performed by actors.

[PRAYER BELL CHIMES]

Ethereal female voice: Death is the last intimate thing we do.

Andrew: Could you quickly step me through your judicial record?

Betty King: Okay, um, first female prosecutor for the Queen for the state of Victoria, first prosecutor for the Commonwealth of Australia, first female silk – together with my girlfriend Lillian – in crime in Victoria, appointed to the County Court in 2000, appointed to the Supreme Court in 2005, retired 2015.

Andrew: Retired Supreme Court Justice Betty King is a woman of many firsts. As notorious gangster Carl Williams found out, she's also a woman to be reckoned with.

Betty King: I just said, 'No remove the prisoner.' That's when he said, 'Oh, you can get fucked.' And I thought, 'That's fair enough, that's an eloquent statement.'

Andrew: Now she has another first to her name: inaugural Chair of Victoria's Voluntary Assisted Dying Review Board.

Betty King: It was such a significant thing that had occurred in Victoria, and I thought it would be an honour to be part of it.

Andrew: But after one year of the law's operation, some are questioning the Board's work.

Stephen Parnis: What we're seeing in Victoria is that there is very little scrutiny of what is happening quietly.

Andrew: How does Betty King make sure the safeguards built into Victoria's assisted dying law are followed to the letter?

Betty King: It's not an easy process, but neither it should be. This is the ending of a life, and it ought to be treated in a serious manner because it's a serious thing to do.

Andrew: And how do those safeguards protect Victorians against coercion?

I’m Andrew Denton. You’re listening to Better Off Dead.

[OPENING TITLES. VOICES OVERLAPPING]

Andrew: During her 40 years practising law, Betty King saw a lot. In her first jury trial, in 1976, what she mostly saw was a room full of men.

Betty King: So, there were 18 defence counsel, two prosecutors, a jury of 12, and a judge and all the witnesses, and there was no other female for the entire time.

Andrew: What was that like for you?

Betty King: Very funny. *[ANDREW CHUCKLES]* The foreman of the jury blew kisses to me during my final address, so I thought my client was pretty safe at that point.

Andrew: Did you win the case?

Betty King: I did.

Andrew: In 2010, Betty leapt to national fame when she presided over the trial of notorious Melbourne gangland figure, Carl Williams.

Betty King: It was bizarre. Roberta Williams was coming in and out, and she’d shaved her head, and she was yelling at people, and my tip staff is running out, telling me all these things before I’m about to walk in. It just felt like it was straight out of a drama that someone had written.

Andrew: For his role in multiple murders, Betty sentenced Williams to life in prison. She told him, ‘You are a killer and a cowardly one.’ Williams wanted to respond.

Betty King: He said, ‘I have a statement I want to make,’ and I just said, ‘No remove the prisoner.’ That’s when he said, ‘Oh, you can get fucked.’ And I thought, ‘That’s fair enough, that’s an eloquent statement.’

Andrew: That night on the news, Williams’ mother Barbara described the sentence as a:

Barbara Williams: Complete injustice. Betty King’s a puppet and she doesn’t deserve to wear her wig and her gown.

Andrew: When she retired from the bench at 65, five years early, she left with affection and acclaim as ‘no-nonsense Betty.’

Betty King: I thought I’d worked long and hard, and I wanted to enjoy the rest of my life and not it to be only about crime.

Andrew: Months after her retirement, the State Government approached her unexpectedly to become the first Chair of Victoria's Voluntary Assisted Dying Review Board.

Betty King: I think they wanted someone who would be seen as fairly no-nonsense sitting in the review position.

[ABC NEWS THEME MUSIC]

Newsreader: Victoria is a significant step closer to becoming the first state to legalise voluntary euthanasia. Lower House MPs have voted in favour of the Dying with Dignity bill…

Andrew: Perhaps she shouldn't have been surprised by the invitation. She had watched on as Victoria's parliament debated the law, and publicly shared her support for assisted dying. For Betty, this was more than just a personal view.

Betty King: I had a case where a fellow – very aged – tried to kill himself and his partner. He was very, very unwell. And he'd been caring for her for a long time. He had a hospital bed set up in the living room, and he'd been her sole carer, and she wanted to die. So, he tried to set up a most ineffective scheme to kill them both. He wasn't going to kill her and just sit around. He was going to go with her. It, of course, failed. So, once it had failed, he rang for an ambulance, told everyone what had happened. And he was charged with attempted murder. And he was dealt with in the Supreme Court because murder can only be dealt with in the Supreme Court. An attempt is the same as an actual completion of an offence, so it carries life imprisonment. And I remember my comments when I was sentencing him, which was to please go home and hopefully your life will go on, but he was not allowed to see his partner any longer. She survived and was placed in care, and he was banned from seeing her. So, he had a punishment worse than anyone else could have given him. And I remember saying when I was sentencing him, 'If we treated an animal and kept them alive in the condition that your wife was in, we would be prosecuted. And yet we prosecute you for trying to end that.'

Andrew: And he was not allowed to see her again? For the rest of her life until she died?

Betty King: Yes.

Andrew: Wow.

Betty King: It tends to make you have a fairly firm view about these things.

[PENSIVE MUSIC]

Andrew: An observer of the parliamentary debate, Betty King would have heard some of the concerns raised by MPs about the government's proposed legislation. It claimed its 68 safeguards made the law the most conservative of its kind in the world. Opponents zeroed in on every aspect of the bill, including the role Betty was about to step into.

Male MP: I note that the physician will self-report to the Voluntary Assisted Dying Review Board, which does not have the capacity to provide a clinical oversight and has no investigative role. This is not a safeguard; rather, a mere checklist.

Male MP: Of course, the Voluntary Assisted Dying Review Board is going to comprise people hand-picked by the minister. There are no grounds for confidence in the impartiality or dispassionate conduct of that Board.

Andrew: So, who does sit on Betty's Board?

Betty King: So, the deputy chair is an intensive care specialist. Then we've got a geriatric physician, a palliative care expert. She was quite opposed to VAD initially. We have an ordinary consumer, someone whose partner had died from an illness. A GP, an oncologist and a palliative care physician. We have a neurologist who works in a faith-based institution and a palliative care specialist again. Then we have a lawyer, as well as a medications safety expert, and a respiratory physician. I think it's a fair variety. They certainly ask questions. There's lots of discussion.

Andrew: The Review Board's task is to oversee the safe operation of the law and report to Victoria's parliament. They review every case, looking at case files online before their monthly meetings.

Betty King: We're looking for things that aren't done correctly, things that don't seem right. So, we ensure that the safeguards contained with the Act are in fact complied with. We might look a bit technical, but I don't think when you're talking about ending someone's life, you can really be too picky.

Andrew: By the end of its first year, the Board's report had some headline numbers: 613 people had sought advice about assisted dying. Of them, 231 had permits issued for lethal medication, yet only 124 ended up using it, with the majority who didn't, dying before they could. 125 doctors had trained to assess for VAD, and 99% of cases were compliant with the Act. I asked Betty for examples of the 1% giving her cause for concern.

Betty King: Technical things: not getting dates right, not getting forms in on time, not reading the forms correctly. But so far there hasn't been anything where I have gone, 'Aww, that doesn't feel right.' And we do look. When you have that many doctors and health professionals on the Board, if what was put forward wasn't remotely within bounds, then people would be going, 'Oh, no, no. That's just wrong.' And we would be doing something about it.

Andrew: But for some doctors, this wasn't enough.

Stephen Parnis: What we're seeing in Victoria is that there is very little scrutiny of what is happening quietly.

Andrew: In September 2020, as Tasmania's parliament was about to debate assisted dying, doctors from Care Alliance, a group of medical professionals opposed to assisted dying, took part in an online forum to warn Tasmanians about how the law was working in Victoria. One was emergency doctor, Stephen Parnis, former vice-president of the Australian Medical Association.

Stephen Parnis: We've had a report released by a Review Board in Victoria talking about the first 12, 13 months of operation of this legislation. It's not an independent report, it reads like an advertising brochure.

Andrew: Another critic of how the law was operating was specialist physician, Dr John Daffy.

John Daffy: There is no safeguard against the wrong diagnosis. There's no adequate safeguard when it comes to mental illness. People that are profoundly depressed and demoralised can actually hide that.

Andrew: In recent years, Doctors Parnis and Daffy have been tag teaming against assisted dying wherever a law has been proposed. In Victoria, 2017, they lost; in the Northern Territory and the ACT in 2018, they won; in WA the following year, they lost again, meaning Australia had two states where VAD was legal, and now the issue was alive in Tasmania, Dr Parnis was invoking the C word: coercion.

Stephen Parnis: I would argue that the existence of these laws are a form of coercion.

Andrew: For years, the threat of coercion has been a repeated line of attack against assisted dying. In Victoria's parliamentary debate in 2017, no danger was more frequently raised.

Male MP: Sometimes the relatives might be wanting to encourage the person to take their medicine – or take their poison, I should say.

Female MP: Prosecution after the fact is not a safeguard, and the chances of proving coercion or bullying behind closed doors are virtually non-existent.

Andrew: The threat of coercion and bullying faced by the elderly is very real. Australia's Royal Commission into Aged Care Quality and Safety uncovered disturbing examples of physical, emotional, and financial elder abuse. So, how do the 68 safeguards in Victoria's Assisted Dying law protect against the most commonly raised scenario of family members coercing an elderly relative to their death so they can get their hands on the inheritance?

Before addressing this question, a reminder: how doctors dealt with assisted dying requests before the law existed.

John Stanton: When I think back over the years, when I've helped people in the end stage of life, there's actually no safeguards there for me.

Andrew: This is Dr John Stanton, GP in West Brunswick. He's been in practice for over 30 years. He remembers what it was like for him to assist people to die without the protection of a law.

John Stanton: There's no peer review. There's no one looking over my shoulder saying, 'Yes, you're doing the right thing or the wrong thing.'

Andrew: And here is Dr Nola Maxfield, rural GP in Wonthaggi. She's been practicing for 40 years.

Nola Maxfield: A lot of it was the doctors would decide or family members would decide, rather than the actual person themselves doing it from an informed viewpoint.

Andrew: So how does Victoria's law improve on that? There are five distinct steps of the assisted dying process. At each step, doctors fill in forms, confirming they have complied with the safeguards. If the information is incorrect, they can't proceed. Here's how the process runs.

[SERIOUS MUSIC]

Female voice: Step one: the first assessment.

Betty King: To complete the process, you've got to have form one, which is the coordinating medical practitioner's first form. So that's the first request, first assessment.

Andrew: To be eligible for VAD, a person needs two separate assessments by two doctors, one of whom must be a specialist in the disease the person is suffering from. Strict guidelines govern how they can even approach the subject of assisted dying.

David Speakman: The law states that a practitioner is not to initiate any discussion about voluntary assisted dying.

Andrew: This is Dr David Speakman, Chief Medical Officer at Peter MacCallum Cancer Centre, also known as Peter Mac.

David Speakman: Any discussion needs to be initiated by the patient. We completely practise that.

Andrew: Sometimes, people don't know who to ask. Sometimes, doctors don't want to hear. So, the government set up the Care Navigator team, social workers and nurses whose job it is to guide people through the many steps of the law. Here's Navigator, Susan:

Susan: Right from the outset, we maintain a technical neutrality, and to clearly not be advocating for voluntary assisted dying. It's a choice for people at the end of their life and if it's something that they choose, then we will support them through that. It's not for everyone. And we always seek to advocate that it's just one option.

Andrew: And this is Navigator, Mel:

Mel: When we go to meet someone, we'll say to them, 'This is the information, this is the eligibility, this is broadly what the process would look like.' And then we would say to them at the end of that, ‘How would you like to proceed?’ And voluntary assisted dying might be one way that they get there, but if that’s not the case, or if it doesn’t work out, then making sure that they know how palliative care could help them achieve that same outcome.

Andrew: If the suffering person is clear they want to access assisted dying, they must be assessed for eligibility.
Andrea Bendrups: In the first assessment, what you’re really doing is checking competency, decision making capacity, and looking for coercion.

Andrew: Dr Andrea Bendrups, a GP and rheumatologist based at Royal Melbourne Hospital, has been in practice for more than 30 years.

Andrea Bendrups: Those are things that, as a treating doctor, I’ve been doing for years. This is not a new – this is not a VAD skill. We’ve all had to ensure patient comprehension and engagement with the process of therapeutics, and that’s called doctoring.

Andrew: For GP Dr Nola Maxfield – as for all VAD doctors – assessing for signs of coercion is a top priority.

Nola Maxfield: You do need to see that they are using their own words and that somebody else is not speaking for them and speaking over them. With VAD, you’re getting down to a much more detailed discussion, and I guess because the person has thought about it in much more detail themselves.

Greg Mewett: We assess those things every day, in our working life.

Andrew: Here’s Greg Mewett, a palliative care physician at Ballarat Health.

Greg Mewett: Is someone being coerced into having surgery? Are they being coerced into having chemotherapy for their cancer? Are they depressed and therefore they’re stopping their treatment? We’ve been doing this for a long time.

Andrew: Greg helped design the training course for doctors to assess for VAD, with a particular focus on coercion.

Greg Mewett: I’m always assessing, when I see a patient, their relationship with their families and how that works. Not just in the VAD sense, but in palliative care.

Nick Carr: You can’t get anything less coercive than a person with a terminal illness ringing up and saying, ‘I desperately need to see you, and this is what I want to see you for.’

Andrew: This is GP Nick Carr. His public advocacy for this law sees patients either referred to him by other doctors or seeking him out directly.

Nick Carr: Any practitioner who’s worked face-to-face with patients, and I’ve been doing that for 40 years, you get quite good at reading the body language, the tone and hesitation, reluctance, uncertainty, lack of conviction is something any experienced practitioner will pick up. I simply don’t believe that coercion is something that would pass the kind of assessments that we are doing.

Andrew: For some doctors, the people seeking VAD will already be their patients. Here’s Professor Phillip Parente, Medical Oncologist and Director of Cancer Services at Eastern Health, Melbourne.

Phillip Parente: So, my patients. I know them exceptionally well. I know the families exceptionally well. And therefore, I can detect coercion, and I’m yet to see it. There’s no coercion at all. Because I’ve got that long standing doctor patient relationship, I know the patient’s personality, and patients are very clear when they request it.

Andrew: It’s not only the doctors’ training and diligence that guards against coercion; it’s the nature of the people who come asking for help.

Peter Lange: My universal experience in people who are pursuing VAD is that they come from all walks of life and all backgrounds.

Andrew: This is Associate Professor Peter Lange, geriatrician and head of the Acute Medical Unit at Royal Melbourne Hospital.

Peter Lange: The common factor is these are people who have control over their own lives; they always have. So, when people talk about coercion, I just find it almost risible because these are people who cannot be coerced. If you were to try, they would run in the opposite direction.

Andrew: Initially, Dr Andrea Bendrups worried that she might not be able to detect if a person was being coerced.

Andrea Bendrups: I thought the greatest challenge was going to be feeling comfortable in myself that there was no subtle coercion from somebody else. You know, ‘Can I really be sure that this person is not being coerced by somebody?’ But I can tell you, these people, there’s not been a sniff of coercion in any of them. The opposite, in fact.

Andrew: Dr Kristin Cornell witnessed the process from the inside as her dad, Allan, reached the end of a long struggle with Motor Neurone Disease. To her eyes, the caution taken to screen out coercion was almost excessive.

Kristin Cornell: There’s that many fail-safes that I just don’t know how you could ever get through coercing someone. You know, you’re assessed for dementia, you’re assessed for appropriateness, you’re assessed for the illness. You’ve got to make the request about 10 times in the end. It’s almost impossible. It’s over the top.

Andrew: Hand in hand with coercion, doctors also assess that the person is mentally competent to know what they’re applying for. Screening for capacity begins the moment someone makes a request. Before doctors become involved, the Care Navigators look for signs that a request to die may indicate something other than terminal illness.

Susan: We get some people with mental health issues coming to us who may not fit within the eligibility criteria, but they're calling out for help and they're suffering. So, if it's a crisis, there has been occasion where we've… have contacted the police. Sometimes we encourage them to tell their usual doctor that they've come to us, so that then the doctor has an idea of where their thinking is.

Andrew: How do doctors determine mental capacity? Here's GP, Nola Maxfield:

Nola Maxfield: You do need to see that they're with it and they know what's going on. All the things that you would normally do for somebody if you're looking to see if they're developing dementia or mental illness that's affecting their cognitive states. So, yes, you do need to see that they're providing sensible answers and having an intelligent discussion with you.

Andrew: Many doctors say that when it comes to assessing patients, determining mental capacity is a core skill, and not just one related to VAD. Here's palliative care physician, Dr Greg Mewett:

Greg Mewett: There's nothing exact in medical science and in healthcare, but you can be as sure as you can be that a person has decision-making capacity. And we make those judgments every day of the week.

Andrew: This is equally true for GP, Dr Nick Carr.

Nick Carr: People forget that we test competence capacity every single day in professional clinical life, because every time we have a conversation with someone, they make a decision about their healthcare, we're making an assumption of competence.

Andrew: Listening to these experienced doctors talk about their work, I thought back to the claim by Dr John Daffy of the anti-VAD group, Care Alliance.

John Daffy: There's no adequate safeguard when it comes to mental illness. People that are profoundly depressed and demoralised can hide that.

Andrea Bendrups: I think that's a statement that people make when they don't want to do it.

Andrew: Rheumatologist, Dr Andrea Bendrups.

Andrea Bendrups: I mean, it's a great out. And maybe there are a few people who might be able to fool people, but I think it's pretty unlikely. And that's why you have two doctors. You're getting two, potentially three, bites of the cherry to make sure that your assessment is accurate – your first assessment is accurate – so that if there is a delirium, if there is a fluctuation, then you wouldn't proceed.

Andrew: For GP, Dr Nola Maxfield, any such warning signs suggest a clear response.

Nola Maxfield: If any of those alarm bells are ringing, then the person gets sent off to have a psychiatric assessment.

Andrew: I asked Betty King if examples of psychiatric assessment had come before the Review Board.

Betty King: Yes, they've been done and uploaded as part of the materials.

Andrew: What percentage of cases have required psychiatric assessment?

Betty King: A small percentage.

Andrew: What did you learn from those situations?

Betty King: One was found not eligible, and accordingly that application stopped.

Andrew: Betty points out that people often wrongly equate depression with a lack of mental competency.

Betty King: A lot of people seem to think that depression equals an inability to make a competent decision. But it's not surprising if you have a terminal illness, that you have a degree of depression. So, most doctors are quite good at determining that and the coordinating doctors, rather than necessarily referring off to a psychiatric report, they say, 'I note a history of depression six months ago, person was treated, et cetera, et cetera,' and they talk about the steps that have been taken in relation to whether or not it affects their cognitive impairment.

Andrew: And it's not just about psychiatric assessment. The law says if a doctor cannot make a clear judgment about any aspect of a person's condition, they must refer them to an appropriate specialist. Dr Bendrups again:

Andrea Bendrups: If I wasn't sure about, say, a respiratory problem, I have the opportunity to say, 'Look, I'm not prepared to make a call based on this assessment. I'd like you to go and see Dr. Bloggs, who's a respiratory specialist, for an independent respiratory assessment so that he can he or she can look at all of the treatment options for the condition that you've got, and to reassure me that you've had all of the things that are useful for your condition.'

Phillip Parente: I don't think it's really rocket science. If they have a cognitive impairment, the provisions within the legislation allow me to have a geriatrician who can assess the patient to get a cognitive assessment.

Andrew: All this testing, consulting, referring to other specialists: is, to repeat, merely stage one of the application process. And once complete, Navigator Mel explains, all the paperwork is uploaded for approval.

Mel: All of the assessments for Voluntary Assisted Dying are housed in one online portal, and in order to proceed, you need to have your assessment approved. So, the first doctor uploads their assessment, it gets signed off by the VAD Board Secretariat, and then you can proceed to the second assessment.

Female voice: Step two: the second assessment.

[PENSIVE MUSIC]

Betty King: Then you have to have the consulting physician's form, which is form two. So, they also have to agree on the diagnosis and the prognosis, and you have to establish residency, citizenship.

Andrew: The consulting physician makes their assessment independent of the coordinating physician, but has also been trained to assess for coercion and competency. To be eligible, the law requires people with an incurable disease to be found by both doctors to have six months or less to live and to be suffering in a way they find intolerable. In the case of neurological diseases, such as Motor Neurone Disease – which can have a longer and more complex trajectory of suffering – the prognosis is for 12 months or less until death. For rheumatologist, Dr Andrea Bendrups, assessment starts before her patient even walks into the room.

Andrea Bendrups: You've already looked at the medicine. So, you've seen the reports, the discharge summary from the hospital, you've seen the letters from their consultants, you've seen their respiratory function tests or their CAT scan reports or whatever, and so you know where they are at medically and you've done that assessment before you even see them.

Andrew: Opponents of VAD argue prognosis can never be an exact science, and many assessing doctors agree. Here's GP, Nick Carr:

Nick Carr: If I've got someone with cardiac disease or respiratory disease, that's my turf. I'm very happy to be a bit clearer about what my view of the prognosis is there. But I think if you get an honest answer from any doctor, none of us can confidently say how long someone has to live when it's as long as six or 12 months.

Andrew: Oncologist Professor Phillip Parente agrees that 100% accuracy in prognosis is not always possible.

Andrew: Have you ever had patients who lived years beyond what you ever imagined?

Phillip Parente: Yep. And the converse is true. I've had patients who I thought were going to live years and only lived months.

Andrew: But, in his experience, these are outlier events.

Phillip Parente: I think oncologists who know their patients are able to give accurate prognoses. It’s what we do. We are trained for not just an assessment for formulating a treatment, but we trained on prognosis.

Andrew: So how do doctors decide that a person falls within the six- or 12-month timeframe? In Victoria, as with similar laws around the world, the great majority of people who apply for VAD are dying of cancer, and their clinical indicators are often as clear as they are grim. Here’s oncologist, Professor Phillip Parente:

Phillip Parente: It’s quite rare for people with rapidly progressing cancer, who have exhausted conventional treatment, or who don’t want conventional treatment, just the natural history of the disease, to live beyond six months.

David Speakman: We have – on a weekly basis – examined every death that occurs here, VAD or otherwise.

Andrew: Doctors at Peter Mac use many indicators to help guide prognosis. Here’s Chief Medical Officer, David Speakman:

David Speakman: So, I think that when you have a lot of experience in cancer land and can see what the trajectory of the patient has been, what types of treatment they’ve had, and what sort of palliative care they’ve had. And to be honest, a little bit about who’s been looking after them, because a lot of these people are with clinicians who will have tried every possible means to alter the natural history of their disease. And when those clinicians are saying, ‘We’ve got nothing more to give, there are no other alternatives,’ then we need to take that on board and, by and large, most of the people that I have seen have fulfilled those criteria.

Andrew: Dr Andrea Bendrups uses similar markers to help her prognoses.

Andrea Bendrups: I’ve got to know that, for whatever the condition they’ve got, their treating subspecialist has said, ‘You’re at the end of the line, I don’t have anything else that I can offer you.’ That’s the starting point.

Andrew: If GP Nick Carr is unsure about prognosis, there is other expertise he can turn to.

Nick Carr: When it comes to complex malignancy, I would defer mostly to an oncologist and their opinion would, in my view, outweigh mine because in a general practice, we don’t deal with them that often.

Andrew: And that oncologist, if unsure about any of their prognoses, may reach out to another specialist, as did Dr Cam McLaren.

Cam McLaren: Sometimes I’ve contacted neurologists and said, ‘How do I prognosticate in this?’

Andrew: And this is another crucial safeguard in the law. If either doctor is concerned the person may not, for any reason, be eligible, they can decline the request. Strikingly, almost all of the doctors I spoke with had done this. Dr Nola Maxfield:

Nola Maxfield: There was one lady who had a neurodegenerative disease, but she was certainly more than 12 months out, from the way her disease was going, and we had this discussion about she didn't fulfil the criteria. I think she was really annoyed that I just couldn't do it for her then and there at that stage.

Andrew: Oncologist Professor Parente has also declined requests.

Phillip Parente: I've denied people access to the legislation who have failed that criteria. And I said, 'I'm saying no, today. That doesn't mean no later on. So please ask again.'

Andrew: As has palliative care physician, Greg Mewett.

Greg Mewett: Yes, I did decline a request that came for a referral from a GP, and it was purely on prognosis, Andrew. There was no doubt. I had a good talk with, and one of our haematologists has done the training, just as a consulting thing, and he said, 'No, clearly this man may have two years, given where his trajectory is,' but I've always said to him, 'We'll revisit this if things change.'

Andrew: The other key requirement for the completion of step two is proof the person applying is an Australian citizen and Victorian resident. As with each part of the process, everything must be in order before a person's application can progress.

Nick Carr: There's a lot of forms that have to be done, a lot of scanning, a lot of uploading of demographic documents around Australia and residency and Victorian citizenship, those sorts of things.

Andrew: Do you get the sense that your actions and those of the other medical practitioner are being scrutinised in real time?

Nick Carr: Oh, very much so, yeah. Heavily, hugely scrutinised

Andrew: Is there any other area of medicine, in your experience, where there's this level of scrutiny?

Nick Carr: Not that I know of. No, this is, *[CHUCKLES]* this is top level.

[PENSIVE MUSIC]

Female voice: Step three: the written and witnessed declaration.

Betty King: Form three is the written declaration by the person that I wish to use Voluntary Assisted Dying. It has to be witnessed by two people. One family member can be a witness, but there must be a totally independent witness as well.

John Stanton: I make it very clear to the witnesses that your role is not just to witness the signature.

Andrew: Here's GP, Dr John Stanton:

John Stanton: It's to witness the person does have the mental capacity, that's their own free will. They know exactly what will happen when they take the medication and so on, and once they get the medication, they don't have to take it. So, the witness needs to be reassured that all that's the case before they can sign as a witness.

Andrew: Care Navigator Susan explains how the legislative requirements for who can be a witness act as a safeguard.

Susan: For example, you can only have one family member, you can't have someone who's a financial beneficiary, and you can't have someone who's involved in your care, or who is running the organisation, the health service. So sometimes it can be quite tricky getting the right witnesses.

Andrew: As with every step of the process, the written declaration is an opportunity for the person applying to reconsider their choice. Reg Jebb remembers the insistence on this from the doctor assessing his wife, Helen.

Reg Jebb: She really laid it on the line, what's going to happen, and just about yelled at Helen's face that, 'Do you want to do this, are you sure, are you sure, are you sure?' And the witnesses are watching all of this, and then they've got to sign that, A) Yes, she wants it, B) she hasn't been coerced, she's doing it of her own free will, nobody's pressing her arm up the back.

Andrew: The written declaration is the second of three requests that a person must make for assisted dying. The first, made verbally to the coordinating practitioner, starts the whole process off. The last can only be made after a set period of time. Navigator Mel explains:

Mel: Part of the law is that the assessments from first to last need to take a minimum of nine days, and that's one of the safeguards about making sure that the request is enduring.

Andrew: And Betty King says there's a good reason for that.

Betty King: That goes to the issue of coercion, that they're mentally competent to do it.

Andrew: To Robbie Caliste's father, Jean, the care taken to make sure his son's decision was his own was crystal clear.

Jean Caliste: The person who was going to make that decision literally had to convince the two specialists or the doctor that this is what he was doing, you know, of his own volition.

Andrew: That the law is demanding and precise has led to a harsh reality for some.

Betty King: We have so many, they get to form three and die, get to form four and die. They don't make it down that path. We've never had a complaint about it being too quick. Only ever had complaints about it taking too long**.**

[PENSIVE MUSIC]

Female voice: Step four of five.

Betty King: Form four is appointing the contact person. They have to then make a final request to use VAD, apart from the written request.

Andrew: The person applying normally appoints someone close to them as contact person, and their main job is to make sure the lethal medication gets back to the pharmacy if unused. Then comes the final request, made verbally by the person seeking VAD. Dr David Speakman sees these three requests – spread out over a minimum ten days – as an important safeguard.

David Speakman: So that there's a clear intention that it isn't made as a one-off when they might have been under the influence of drugs, and/or anything else

Andrew: Most people who apply for VAD will end their suffering by drinking a lethal medication. Only they can choose to drink, or not: the ultimate act of choice. But what of those so debilitated by their illness they're unable to act on their choice? In these desperate circumstances, the law does allow a doctor to inject the medication but, once again, as Dr Andrea Bendrups recalls, there are strict protocols.

Andrea Bendrups: The VAD Board requires for the physician-assisted, you have to fill in a form which is signed by the witness, the contact person, and then that goes back, sort of closing the loop to say, 'Yes, the stuff was prescribed, and it was given out and then I carried it to the facility, I injected it, and the daughter saw it happen and confirms that it did happen.'

[PENSIVE MUSIC]

Female voice: Step five: the final application for the medication to be prescribed.

Betty King: Form five is a compilation where you attach all of them and all that information is re-input and sent off to the Secretary. The Secretary then makes a decision, then the permit is granted. Once it's granted, the doctor then contacts the Pharmacy and they give them the permission to write, basically, the prescription.

Andrew: Even at this final stage, after the prescription has been written, a final safeguard against coercion. Jacquie and Nicole Robertson's mother, Kerry, was the first person to use Victoria's law. Here, they describe what happened when the pharmacists delivered the medication.

Nicole: They walked us through step by step, making sure Mum was well aware at every stage exactly what happens with the medication.

Jon Faine: And at every stage could your mother have said, ‘Okay, I’ve changed my mind’?

Nicole: Absolutely.

Jacqui: Everyone was very clear that even if she was dispensed the medication, she was under no obligation to take that medication at any time. It was completely up to her.

Jon Faine: Right through to the point where it’s already mixed and it’s there.

Jacqui: Absolutely.

Jon Faine: And does she pick it up to drink?

Jacqui and Nicole: Yes.

Jacqui: And even if it had been mixed, and she changed her mind, they were very clear that if that happens, and she changes her mind, but she would like another kit, they can dispense another kit. So, at no point in time is she obligated to take that.

Nicole: There were also very strict instructions with what to do with the medication if, you know, there was a point where it was mixed and not used or if it wasn’t used at all.

Jon Faine: So, everything’s been thought through?

Nicole: So thought through.

Andrew: Even at this eleventh hour, sometimes the pharmacists will make the tough call.

Michael Dooley: There may be a difference between the time that we see them and the time that the doctors had seen them.

Andrew: This is Professor Michael Dooley, head of the Statewide Voluntary Assisted Dying Pharmacy Service.

Michael Dooley: There’s been a small number where they haven’t been able to demonstrate either competency or haven’t been able to demonstrate they’re able to take it, and those instances, we’ve had to make a difficult decision to say ‘no.’

Andrew: This happened with one of GP Dr John Stanton’s patients.

John Stanton: He was an elderly man with a mesothelioma of his abdomen, and when I saw him, he met all the criteria, and by the time the Statewide pharmacists went to visit, he… he no longer had the mental capacity to make decisions, so he died receiving palliative care and not taking the medication.

Andrew: The repeated questioning to test for competency and coercion is, Betty King says, tough on the patient.

Betty King: The most common feedback we get, in terms of a complaint, is how often they have to tell people they want to use VAD.

Andrew: Doctors find themselves challenged, too, by the need to cross every T and dot every I.

Phillip Parente: I would say, out of all the forms that I do, the application for VAD is the hardest to get correct.

Greg Mewett: Some of the bureaucratic detail drives me and other VAD doctors nuts. You know, you spell the name of the street incorrectly and they send it back to you. It can be quite tiresome.

Andrew: No detail, it seems, is too small for Betty King's attention.

Andrea Bendrups: I've certainly been in that position where I wrote the wrong date in and I got a letter back from Betty King saying, 'You know, this form isn't da-da-da-da.'

Andrew: But, for this, Betty is unapologetic.

Betty King: It's not an easy process, but neither it should be. This is the ending of a life, and it ought to be treated in a serious manner because it's a serious thing to do.

Andrew: And Care Navigator Mel believes that, for some doctors, all this detail has had unanticipated benefits.

Mel: Some of them really feel like it's made them better doctors. Because they have to record what the person's reasons are, it necessitates a really person-centred conversation about where they've come to, not just in their illness, but in their life.

Andrew: Doctors are also aware that the Board has the power to do more than insist that the forms be filled out correctly.

Betty King: We have the power to refer to AHPRA, the police, the Secretary of the Department of Health, Births Deaths and Marriages, and the Coroner.

Andrew: If a doctor were to break the law, significant penalties apply: up to five years in prison for falsifying a formal record, making a false statement, or inducing someone to request VAD.

Betty King: So, the fact is that we review as deeply as we do in terms of each case should be a fairly major deterrent to any medical practitioner who is inclined to think, 'Oh, well I can just slip this through.'

Andrew: And you have, in fact, referred one case to AHPRA, who are the Australian Health Practitioner Regulation Agency. Can you talk me through what happened?

Betty King: I can tell you that it was a failure to complete a form correctly. But we thought it was of a level that required the conduct to be examined, but we had no problem in that the person was eligible. It was perfectly valid to grant the permit.

Andrew: Betty wouldn't divulge details about the case. Then, unexpectedly, the doctor outed himself.

Nick Carr: My hearing is Wednesday next week.

Andrew: GP Nick Carr was up to step three, getting the person's written request witnessed and signed.

Nick Carr: There were a lot of people in the room, and he was kind of slightly holding court and was trying to get the paperwork done. And finally, when we uploaded it to the Board, they sent back and said, 'Well, your two adult witnesses and you have signed to say that you've witnessed the signature, but there's a blank space where his signature should be.' *[OH.]* The patient hadn't actually signed the form. *[WOW.]* And so, I got it signed and sent it. But then I got a letter from the Board saying that I had broken subsection 48C or something by witnessing that he'd signed when he hadn't. And I've now been reported to the medical board.

Andrew: Which, while you wouldn't like that, from the point of view of the due diligence of the law, that's good to hear.

Nick Carr: Yes. I mean, they've been very careful with that oversight of it. I just mucked it up because this was – I don't know – about the seventh or eighth written declaration I'd done. I've no idea how this happened, but I certainly won't do it again.

[SOMBRE MUSIC]

Andrew: For all the Board's insistence that the letter of the law be carried out, arguments are still made – as they were in the Parliament – that it cannot prevent a wrongful death.

Male MP: I note that the physician will then self-report that all of these so-called safeguards in the bill have been met to the Voluntary Assisted Dying Review Board, which does not have the capacity to provide a clinical oversight and has no investigative role. This is not a safeguard; rather, a mere checklist.

Andrew: And it's true; the Board doesn't offer clinical oversight of the doctors reporting to it, as Betty King explains.

Betty King: We don't sit and say, 'Well, we disagree with your clinical judgement,' because we don't go back and examine every document in that person's case history. You have to have a degree of reliance upon those who actually make the decision.

Andrew: What's also true is that those involved in assessing a patient for VAD are experienced professionals, and that they are just one part of a much larger system of medical practice. Put together, they create a level of scrutiny for doctors unmatched in any other area of medicine.

I put the same question to all the health professionals I spoke with: when a person applies for assistance to die, how many different eyes are on them as they go through the system?

Phillip Parente: The palliative care nurses in the community, all the nursing staff – and it's not just one nurse, there's multiple nurses. So, all the oncology nurses would know, they're all the eyes and understand the patient's journey.

Susan: There could be the assessing doctors, and then another doctor for prognosis, and then another clinician for capacity or for psychological assessment. And then there's the Pharmacy, then the Secretariat behind the scenes, reviewing the documentation. So, there's many people who have eyes on the case.

Phillip Parente: There's always a GP that would know the patient. They might not be directly involved. Usually they are, but that's another eye.

Mel: That is why those safeguards – all 68 of them – are there. It would be incredibly challenging for you to coerce someone.

David Speakman: And then, over the top of all that is the Board, these independent groups who are watching every one of these cases as they roll through. An additional safeguard that people aren't practising outside the realms of what's expected.

Molly Carlile: The members of the Board, there's a lot of expertise around that table from a whole lot of different backgrounds. And it would be very difficult for anything to slide past unnoticed.

Andrew: This is Molly Carlile AM, a senior palliative care leader and member of the Review Board.

Molly Carlile: If at any point along that path there is an anomaly, that is queried. It doesn't go further until that anomaly is addressed. So, if someone was trying to game the system, it just wouldn't work.

Andrew: So many eyes, none more watchful than Betty King's.

Betty King: They can't cut corners. They just can't. Because they have to complete all of the requirements, or it's not compliant. End of story.

Andrew: I think back to John Stanton's description of what it was like when there was no law.

John Stanton: There's actually no safeguards, there's no peer review, there's no-one looking over my shoulder saying, 'Yes, you're doing the right thing or the wrong thing.'

Andrew: For Betty, whose life is dedicated to law, this was never sustainable.

Betty King: And I'm sure that they were well intentioned, but it's much better, I think, if it's regulated. It becomes a real choice, then, and a known choice of the patient, not a choice of the doctor**.**

[SAD MUSIC]

Andrew: Yet there is a cost to this level of scrutiny and multiple assessments and proof of mental state required under Victoria's law, and that cost is difficulty of access. Here's Review Board member, Molly Carlile:

Molly Carlile: So, if English isn't your first language, it would be complex. If you don't happen to have a GP who is prepared to either support you or refer you on to someone else who will, it can be extremely difficult. If you don't know about the existence of the Statewide Navigator service, it can be extremely difficult. If you have a diagnosis that is somewhat unusual, and there's not a specialist in that illness who has either done the training or who is willing to do it, it can be extremely difficult. For people who maybe don't have a high level of education, maybe are in a lower socio-economic demographic, maybe are from a culturally or linguistically diverse background. Because Voluntary Assisted Dying cannot be openly promoted or openly discussed, or the conversation initiated by a health professional, it means that the person who wants to pursue that path needs to know exactly how to go about doing it.

Andrew: Making access even more difficult is evidence of what might be called 'coercion in reverse': efforts to discourage people from pursuing their legal right to VAD. Betty King calls these 'the known unknowns.'

Betty King: There's a few that actively try to dissuade, and that's a complete reversal of conscientious right to object to it. You don't have the conscientious right to change someone's mind. Anecdotally, we've had feedback about the person being told that it would take too long, you'd be dead before this, palliative care is infinitely better, this is a painful process… The number who go to doctors and make a request and get, 'Oh, no, no, you don't qualify,' 'Oh, no, that's not for you.' That they went to their local GP and they said, 'Yes, I'll do the training,' and five weeks later, nothing had happened. Then they've come back then they've said, 'Oh, no, I've changed my mind. I don't think you're right for it anyway.' So, if they're not strong enough to go off searching, and to give up on their own GP, you know, it's a brave thing to give that up and go to a stranger.

Andrew: The repeated refrain from everyone I've spoken to in this series is of how rigorously the law is applied and of how often the people seeking its help have to prove their eligibility.

When you add to this the many obstacles to access outlined by Molly Carlile and Betty King, it’s easy to see why Victoria’s former Health Minister, Jill Hennessy, once said that coercing someone to die using the law would be harder than Ocean’s Eleven.

Though ever watchful, Betty King is confident this is a system that works.

Betty King: I don’t know how, really, you’d coerce someone. It’s hard to duress someone for months and then duress them into actually saying, ‘I want to die,’ and duress them into picking up the medication and drinking it. Yes, I think you have to deeply desire it to choose the path and to stay the path.

[THOUGHTFUL MUSIC]

Andrew: There is one final safeguard against coercion. It’s not written into this – or any – law, yet it’s something that doctors see time and again: courage.

Andrea Bendrups: Every other patient has had relatives trying to talk them out of it, you know, tearful, ‘We don’t want you to go.’

Phillip Parente: It takes a lot of courage and it’s taking a lot of soul searching, a lot of discussions with their partners and their children or their parents, relatives, best friends prior to coming to me. It’s a humbling experience.

Andrew: Courage. It’s also what families see. Lisa Hogg with her mum, Margaret:

Lisa Hogg: Having that cup in your hand and taking that first sip, knowing that you’re going to die if you drink this, it took enormous courage.

Andrew: Kristin Cornell with her dad, Allan:

Kristin Cornell: He was so brave, you know, and I think that full-on moment of realising that you have it and you can do it. It’s very confronting, because it’s easier to give up, I think, at that point.

Andrew: Katie Harley with her dad, Phil:

Katie Harley: Till the day I die, it’ll be the most courageous thing I’ve ever seen anyone do. I feel like Dad’s courage just… it can’t be measured.

Andrew: The courage to say goodbye to everything you love, to all you’ve ever known: the final safeguard against coercion, one that no review board could ever measure, and one that Betty King sees, too.

Betty King: It takes determination. You’ve got to take all of these steps. I’m in awe of all of these people who go through it. I just… I admire their courage; I admire their strength.

[MUSIC: ‘LOYDIE’S ANGEL’ BY JORDAN LASER]

Andrew: If you'd like to support the work of Go Gentle or find out more about us, go to our website at gogentleaustralia.org.au

In the next episode of Better Off Dead: Colin was a beloved 79-year-old Classics lecturer, dying of cancer.

John Stanton: He'd made the decision that he wanted to end his life now.

Andrew: Victorian law gave him that right, but Colin lived in a nursing home run by the Catholic Church, who are guided by a different law.

Andrea Bendrups: He was completely legally within his rights, and then to have those buggers refuse was just so not right.

Andrew: Victoria's law says an individual may conscientiously object to taking part in VAD, but when does conscientious objection become obstruction?

Deb: I couldn't understand why it is better for someone to suffer and have a horrible death. It just seemed to make no sense to me at all.

[CLOSING CREDITS]

VO: Season two of Better Off Dead is created, written, and presented by Andrew Denton, with Beth Atkinson-Quinton, Martin Peralta, Kiki Paul, Steve Offner, and production assistance from Alex Gow. It is a co-production of Go Gentle Australia and The Wheeler Centre. Follow wheelercentre.com/betteroffdead to learn more about the people and ideas from each episode.

['LOYDIE'S ANGEL' CONTINUES]