

## Better Off Dead

Transcript for season 2, episode 11: The End of Life Lottery

**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](http://wheelercentre.com/betteroffdead).

*[PRAYER BELL CHIMES]*

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

**Andrew:** This episode of Better Off Dead is the third of four that provides information about some of the values and assumptions underlying Voluntary Assisted Dying not just in practice in Victoria, but as it continues to be debated around Australia.

Over these episodes we will look at:

- Whether palliative care can address all suffering;
- Who gets to decide how much suffering you can handle and pain relief you can be given;
- Different beliefs around dying; in particular, dying as a time of spiritual growth;
- And what it can mean to die in a system whose values you don't share.

These are important public interest issues. You will hear a range of views expressed across these episodes, and we accept that all participants in end-of-life care are sincere in their views and in seeking to provide the best possible care for the dying.

Wherever you land on these issues, you may want to think about them. Particularly, you should ask yourself, 'What choices do I want?' and, just as importantly, 'What choices do I have?'

*[MUSIC]*

**Andrew:** The relationship between people of faith and Voluntary Assisted Dying is anything but black and white.

**Katie Harley:** Yeah, well. We're Catholic, and our local priest couldn't have been more supportive. He conducted Dad's service. He visited Dad before he died.

**Andrew:** This is Katie Harley. The year is 2019 and her dad, Phil, demolished by cancer, was shortly to die using Victoria's Voluntary Assisted Dying law.

**Katie Harley:** He came in and he said to Dad, 'Would you like me to give you a final blessing?' And Dad said, 'Yeah.' And we were all gathered around the bed, and after he'd

finished the formality, he said to Dad, 'Look, Phil, I guess there's no mistaking what's going on here. Is there anything you'd like me to say during your ceremony?'

**Andrew:** Near to death, and in great pain, Phil struggled to respond. Overwhelmed by the emotion of the moment, Katie couldn't answer either.

**Katie Harley:** It was my husband, Ryan, who could sense it was a bit hard for me to respond for Dad, and Ryan is a man of very few words, and he looked straight at the priest and he said, 'Look, mate, I think I speak for Phil when I tell you that he just wants enough holy shit to get him in the gates.' Honestly, it just brought the house down. And if Dad was in his best state, I'm pretty sure he would have said it exactly the same way.

**Andrew:** It's a shining example of Christianity at its most nimble and most loving, but when it comes to assisted dying, it's not the kind of Christianity endorsed by The Vatican. In this episode: how the dictates of the faraway Vatican can extend to what happens as you die in Australia.

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

*[OPENING TITLES. VOICES OVERLAPPING]*

**Andrew:** As I've been making this series, I've met devout Catholics such as oncologist Professor Phillip Parente and senior palliative care leader Molly Carlile, both of whom have reconsidered their opposition to assisted dying on the grounds that patient-centred care means not putting their own worldview ahead of patients' needs; I've heard of Catholic hospitals finding ways to quietly help people seeking to use VAD without compromising their own ethics; and I know of people working within the Catholic health system who compassionately support such choices.

But I've also learnt of more troubling things: of dying patients moved from palliative care wards in faith-based institutions, and to unfamiliar beds, when they choose VAD; of people who are living in Catholic care and mortally ill, terrified that their legal right to access life-ending medication will be blocked, as it was by Mercy Health in Colin's story earlier in the season.

Perhaps most disturbing of all: of the family visited by a senior Catholic palliative care physician who came, uninvited, to their house, to accuse the son of coercing his mother into choosing VAD, then attempted to talk the dying woman out of her choice. Her husband told me, 'I almost threw the doctor out of the house. It's very distressing to see your wife of 44 years essentially harassed by someone.'

Polling in Australia over many years consistently shows that support for assisted dying amongst Anglicans and Catholics sits at around 70%. It's not a view shared by the Catholic hierarchy. At the commencement of Victoria's law, the Catholic bishops of Melbourne issued a statement saying:

**Male voice:** We cannot cooperate with the facilitation of suicide, even when it seems motivated by empathy or kindness.

**Andrew:** The language of The Vatican is stronger still. In 2020, in its latest encyclical on euthanasia and assisted dying, it proclaimed:

**Male voice:** Euthanasia is an intrinsically evil act that no end can justify. To end the life of a sick person is to take the place of God in deciding the moment of death.

**Andrew:** In the last episode, I talked of how The Church sees dying as an important time for spiritual growth. In the words of Catholic Health Australia's Code of Ethical Standards:

**Male voice:** Even when suffering and death cannot be eliminated, they can nonetheless acquire a positive, life-giving and redemptive value, especially from the perspective of religious faith.

**Andrew:** I've heard no more vivid expression of this than the words of palliative care physician and committed Christian, Dr Megan Best, speaking in 2013 to the Centre for Public Christianity.

**Megan Best:** There seems to be a desire for some people to go from a space where they're feeling extremely healthy to a place where they're dead without having to go through the process of dying at all. In a society which has lost touch with the meaning of suffering, there is also, quite understandably, a loss of the willingness to endure it.

**Andrew:** Redemption through suffering, finding meaning in a natural death; these are powerful beliefs. But what if they're not yours? What can it mean to die in a system whose values you don't share?

*[SOMBRE MUSIC]*

**Alex Broom:** I think the core of the debate here is: what is the purpose of suffering? And what responsibility do we have as a society, the state, the medical profession, to ensure that purposeless suffering doesn't occur?

**Andrew:** Alex Broom is a Professor of Sociology at the University of New South Wales, doing research into end-of-life care. In 2011, he spent six months embedded in a Catholic hospice – a hospice being a place where palliative care is delivered.

He recalled one terminally ill man who had overdosed on morphine so he could have an ending – in his own words – 'of his own choice.' His neighbour found him, and he ended up in the hospice.

**Alex Broom:** And his first words to me were, 'Alex, they wouldn't let me die. So, I'm here.'

**Andrew:** Professor Broom observed how the hospice reacted to his distress.

**Alex Broom:** The hospice staff said to me, 'He's just not in a good place. He is psychologically not well, and he will get to the point where he accepts that this is just part of the process.' I think what that captured was how an organisation and how a profession, if it's not careful, can instil particular values around what is a good death, and can subtly remove or disallow people's opportunity to make decisions for themselves.

**Andrew:** He saw the benefits that hospice brings.

**Alex Broom:** The hospice reduces a sense of burden on one's family, on one's community. For some people, it was an occasion to make the most of the time that was left.

**Andrew:** But with those benefits, the unspoken obligation.

**Alex Broom:** What people don't realise is that they're not just entering into a clinical environment; they're entering an environment with particular values and certain ideas about what is okay or not okay, and the nature of suffering. And by entering into that, the patient and the family is almost embarking on an unwritten contract: that death will be not on my terms, but on the terms of the institution

**Andrew:** For Professor Broom, this one-size-fits-all approach is problematic.

**Alex Broom:** If we know anything, it's that dying is done in as many ways as people die. Each person defines a good death in their own unique way. Some people don't want to be medicated to the point of having no pain, because they lose a sense of clarity.

**Andrew:** And pain is just one part of the picture. More difficult to address is the question of suffering. For some, suffering is part of God's plan.

**Alex Broom:** There are people that say to me, for example, 'God will take me when he wants to. suffering is just part of it.'

**Andrew:** For others, though, the suffering can be intolerable.

**Alex Broom:** The loss of a person occurs often way before the point of death. You get that period of time when there is such suffering that there isn't much left of the person.

**Andrew:** And this is when the hospice's values can come into play.

**Alex Broom:** These organisations are often infused with ideologies around what dying should be and what it means. The idea of an afterlife and this dying process as essentially a rite of passage is very powerful. It all comes down to what the collective around you think is appropriate or not, and I remember an elderly man who said, 'I thought they'd help, but you don't get help. They just keep you alive.' Now, I don't think that's necessarily true to the philosophy of palliative care, but that was his experience.

**Andrew:** I asked him what happened when the people he observed in hospice asked for help to die?

**Alex Broom:** The response was, 'We will send the psychologist to see you,' basically.

**Andrew:** So, there must be something wrong with you to think this way?

**Alex Broom:** Unfortunately, yes. Essentially, what it becomes is, 'If you don't agree with the model and you want to end your life, you've got depression, or you've got a mental health issue that needs to be resolved.' What that's doing is essentially imposing clinical solutions whichever direction you go.

**Andrew:** It's a Catch-22: because you're dying, you're depressed. Because you're depressed, you're not fit to decide, so we can't let you die.

**Alex Broom:** What it is, is an approach to pushing people along the pathway to acceptance. And the question I always raise is, 'Acceptance of what?' I just think that's so, so disrespectful to the fact that we are on different trajectories, each of us. And it may be that some of us are simply not going to die in the model that the palliative care and the hospice movement would like. Those who view the hospice model as inhumane... a regular statement was, 'You wouldn't let a dog go through this.'

[PENSIVE MUSIC]

**Andrew:** Palliative care has strongly Christian roots. Its central tenet is to 'neither prolong nor hasten death.' Walking that line without adding to a dying person's suffering sets many challenges.

I got a strong sense of this back in 2015 when I was invited by Professor Richard Chye to spend a week observing and interviewing his palliative care team at Sydney's St Vincent's Hospital. I live close by and was able visit at all hours. What I saw impressed me deeply. I got to do the rounds and to sit in on the weekly staff meeting. My notes from that week give a snapshot into the complex business of bodies and lives breaking down:

- The 93-year-old with cancer whose oncologist wants to keep giving chemotherapy. Her palliative care doctor has told him *'forget it'*;
- The 43-year-old with mesothelioma. It's creeping now, from the right to the left side of his chest. He's on 'bucketloads of opiates' but the pain never goes below 4 out of 10. Sometimes it hits 8;
- The man in his 70s with cancer and lifetime regrets, who's estranged from his son. 'I suspect he doesn't have a lot of time,' his doctor says. A social worker is to be brought in;
- And the mother from Chernobyl whose 29-year-old daughter's cancer, now spread to her bones, had been blasted with everything. The daughter, distressed, knows she is dying. She's had enough. But for the mother, 'She's my daughter. I want to keep her alive.' There had been a shouting match, the mother furious with the palliative team who supported her daughter's wish only for comfort care.

The experience of that week is one of the reasons that, along with my advocacy for assisted dying, I strongly support more funding for palliative care. I think the work they do is remarkable and important.

It also left me wondering what it must be like, at the end of a life successfully navigated, to lose control over your destiny?

Like all Catholic hospitals, St Vincent's is guided by Catholic Health Australia's Code of Ethical Standards, whose mission statement says:

**Female voice:** A healthcare organisation bearing the name 'Catholic' has a special responsibility to witness to the presence of Christ and to Catholic teachings about the value of human life and the dignity and destiny of the human person.

**Andrew:** Professor Richard Chye has headed up their palliative unit for 23 years. He also holds the position of Adjunct Professor of Palliative Medicine at Notre Dame, a Catholic University.

A vocal opponent of assisted dying, he rejects any suggestion his opposition is based on religion. In a 2017 article entitled, 'We do not like to talk about death – but that doesn't make euthanasia the answer' he wrote:

'I am not religious. I do not follow a faith. While I work for a Catholic healthcare organisation, my views are based on my longstanding clinical experience and medical evidence, not on dogma. There is no Church twisting my arm.'

When I asked for his definition of a dignified death, he replied:

**Richard Chye:** That love is still expressed by all, between patient and family, and that patients are able to slip away in their sleep when it's time. And therefore, it's not for me to say when that is, because it's the patient and his or her maker that decides when that will happen.

*[PEACEFUL MUSIC]*

**Andrew:** Everyone I spoke to at St Vincent's, including Professor Chye, could recall bad deaths – not many, but vivid. Despite ours being rated amongst the best in the world, palliative care has its limitations and, as Professor Chye acknowledged, the absence of hastened death means that some do suffer.

**Richard Chye:** It is normal for me to say, 'I wish I could give you something that will kill you earlier so that you don't have to go through that suffering.' That's a normal emotion to have. And again, I think if you don't have this emotion, then I think I will be worried about myself and how I look after my patients.

**Andrew:** 'What then?' I asked.

**Richard Chye:** I walk with the patient. I say to them, 'Yes, we've done our best to control your pain. Yes, the pain is still there, but I will help you live with that pain.'

**Andrew:** And if those patients make rational and persistent requests for a hastened death – as Palliative Care Australia acknowledges some do – how would Professor Chye respond?

**Richard Chye:** I would say to them that, from my own morals, I would help them with their symptoms and their fears to the best of my ability, but I would not see it as my moral role and my ethical role to end that patient's life, because I don't believe in that. Law doesn't guide me. It's my ethics and my morals that guides me more.

**Andrew:** I see. Are there people who refuse treatment, all treatment, including food and water, because they wish to die?

**Richard Chye:** Yes, they do.

**Andrew:** How long does that take? If you have gone off food and water, how long does it take a human body to shut itself down?

**Richard Chye:** That's a very good question, and I've seen patients go in two or three days and I had a patient who went after three weeks, so it varies, and it is according to how much food have they consumed or were given just prior to stopping.

**Andrew:** My sense is that to refuse food and water is a painful way to go.

**Richard Chye:** I think not physically, but psychologically, I think it is a very painful way to go, and I remember a patient who decided to stop eating and drinking, and she was told, 'If you do that, you will be dead in two or three days.' She committed suicide because it hadn't happened after two weeks.

**Andrew Denton:** Wow, that's a terrible thought! So Palliative Care Australia will accept patient autonomy when it comes to refusing food and water...

**Richard Chye:** Yes.

**Andrew Denton:** But they won't accept patient autonomy when it comes to requesting a faster and more merciful death. Why is that?

**Richard Chye:** I think Palliative Care Australia, and I guess also from my point of view, we are very keen to understand what patients want. If a patient wants to stop treatment and die as a result of their illness, then that's something we would be very happy to accept, especially when the treatment was likely to cause more burden than benefit, then yes, by providing good palliative care, by providing good psychosocial and symptom management, then that's the right thing to do for that patient.

**Andrew:** I thought long and hard about this troubling proposition: that a slow, painful death by dehydration and starvation is seen as ethically acceptable, but a quick and painless one is not. The reasoning from doctors who oppose assisted dying is that withdrawal of food and

fluids is often a natural part of the dying process, and that is largely true. But it doesn't guarantee a good death.

When I asked Professor Chye to whose benefit a patient in that situation was being kept alive, he told me:

**Richard Chye:** I think that patients who live do provide some benefit for the rest of the family and for themselves.

*[PENSIVE MUSIC]*

**Andrew:** In that 2017 newspaper article where Professor Chye argued his opposition to assisted dying was not based on any religious belief, he wrote that bad deaths could be addressed by more funding for palliative care and better training for health professionals.

This argument – and its companion, that we can't have assisted dying until everyone has access to top-class palliative care – is the one most frequently run by doctors against VAD, particularly those within the Catholic health system. And, as we heard in the last episode, it's the argument that has been most effective in persuading politicians to reject assisted dying laws.

Two days after Professor Chye's article appeared, in the same paper, Sydney woman Shayne Higson replied. 'Reading this made me angry,' she wrote, 'because my mother had the best available palliative care. Her doctor in her last days was Professor Richard Chye.'

Shayne's story of her mother, Jan's, suffering is one of many that have come to us at Go Gentle over the last five years.

**Shayne Higson:** Her quality of life had deteriorated to a point where she couldn't read, she couldn't write, she could hardly speak, she was bedridden.

**Andrew:** Jan had an aggressive form of brain cancer which was causing terrible seizures.

**Shayne Higson:** She was seizing for *[SIGHS]* well over an hour. She said it was like a giant thrashing around in her body.

**Andrew:** Of all the terrifying things happening to Jan, this was the worst.

**Shayne Higson:** She said, 'Whatever you do, do not let me have another seizure.'

**Andrew:** After being hospitalized and put on anti-seizure medication, she was nursed at home by the family, with help from palliative care teams.

**Shayne Higson:** She'd lost all feeling down one side. She felt that her body was already half dead.



**Andrew:** Jan's wish was to die at home, but her condition worsened, and it was decided to move her into a private hospital. Like many people, Jan always believed that when the time came and her suffering became too much, doctors would 'do something' to help her.

**Shayne Higson:** She was very clear what she wanted, and she'd said it right at the beginning as well. But... but they, you know, they're not allowed to. That's the thing: once she went into hospital, that's when I really realised that it's just not allowed.

**Andrew:** When you spoke to the medical staff, you said to them clearly, 'My mum wants to be knocked out.' Do you recall what they said to you in response?

**Shayne Higson:** They actually said, 'I think your Mum might have depression.'

**Andrew:** So, I've got this picture clear. She was within a couple of weeks of death at this point.

**Shayne Higson:** Yes.

**Andrew:** She had a major brain tumour.

**Shayne Higson:** Multiple.

**Andrew:** Multiple tumours, was clearly in pain and her body was shutting down all over the place, and they said, 'She may have depression.'

**Shayne Higson:** Yes. Yeah. Mum didn't really like when the palliative care doctor came because [SIGHS] – I don't know – Mum wasn't religious, and just the manner, the sort of questions that were being asked, and I know that he meant well, but coming in and saying, 'Well, Jan, how are you feeling?' and she'd say how she was feeling. This was early on when she could talk. And when she started saying, 'I just want to be knocked out,' and he said, 'Why?' she said, 'Because I want to shut down what I'm thinking.' And he said, 'Well, what are you thinking about?' I mean, she just sort of looked... you know. If she was the sort of person that would swear, I think she would have sworn at him, because, you know, like what do you think she was thinking? I think that's what she said: 'What do you think I'm thinking about?'

**Andrew:** To be clear, even though Jan was under Professor Chye's care, he was not the doctor asking these questions. Shortly after that visit, Shayne got a call from a psychiatrist asking to speak to Jan. When she explained that her mother had brain cancer and was unable to speak on the phone, he simply said, 'Sorry'. For Jan, the wait for relief was inexplicable. Shayne will never forget her mother's description of what being made to endure those last days felt like.

**Shayne Higson:** She said things like, 'Why are they torturing me? Why are they so cruel? This is torture.' And it was. It was torture to force her to endure that end.

**Andrew:** To speed up her dying, it was decided to take Jan off medications, including the ones that stopped her seizing.

**Shayne Higson:** On the second night, she was thrashing her head from side to side, and the leg was going up and down, up and down, up and down. And again, we called in the staff and tried to get medication that would ease that suffering and the distress and agitation. When she didn't stop shaking, we said, 'Can you give her more? It's not working.' He said, 'I can only give her this amount and every 15 minutes. I'm not authorised to give her any more. If I give her more, it might end it.'

**Andrew:** So, how many nights did this go on altogether?

**Shayne Higson:** Five. Five days.

**Andrew:** And at no point was anyone prepared to go, 'We can do more'?

**Shayne Higson:** No. No, no, no. Not a nurse or doctor or anything.

**Andrew:** You must have all felt – and above all your mum – completely powerless in this situation.

**Shayne Higson:** Yes, yes, completely powerless and angry, really. Really upset that at such a terrible time that you are sort of battling this. You know, it just shouldn't have to be like that. At one point my older sister, she said, 'What are we meant to do? Go down to Kings Cross on the street and try and score heroin or something? Like, what are you saying? What choice do we have?' We just couldn't believe what was happening at that end stage.

**Andrew:** Like everyone I've spoken to who's been through this, Shayne had nothing but praise for those working on the wards, who were attentive and sympathetic, but none of them had the power to override doctors' orders. Determined no-one else should suffer like her mum, Shayne gave up her career as a photographer to work full-time on law reform. Eight years later, she's still at it.

We wrote to Professor Chye, sending him Shayne Higson's account of her mother's death, as well as the views expressed by him in our 2015 interview, inviting him to make comment and, if appropriate, correct the record. He did not respond.

*[PENSIVE MUSIC]*

**Andrew:** It is a deeply complex area: when to sedate for pain, how much to sedate, and how to weigh the individual conscience of doctors and carers against the pain, suffering, and sometimes desperate requests of patients.

As Professor Janet Hardy from the University of Queensland's Faculty of Medicine wrote in a 2000 *Lancet* editorial:

**Professor Janet Hardy:** The concept of sedation causes considerable unease in many palliative care workers, most of whom are ardently opposed to any form of euthanasia.

Sedation as the best means of symptom control in the dying patient is under-used because of fear of employing 'terminal sedation.'

**Andrew:** Terminal sedation: the alternative to assisted dying – held up by palliative care – under which all food, treatment, and water is withheld while you are sedated into a coma until you die.

Complicating matters, it's an area with no clear guidelines, as Professor Lindy Willmott from Queensland University of Technology's Faculty of Law wrote to Go Gentle in 2017.

**Professor Lindy Willmott:** There is no law in Australia that specifically defines or regulates 'terminal sedation.'

**Andrew:** Terminal sedation is used in institutions of all kinds: faith-based, government-run, private, public. Beyond the reality it can lead to a lingering death – which can be emotionally painful for the family to witness – it has two significant limitations.

The first is it doesn't prevent suffering. Rather, terminal sedation is a response to suffering that is already happening, an acknowledgment that it can no longer be controlled. 'Refractory symptoms,' they're called. These can be multiple, and happening simultaneously, sometimes over days, or weeks, or even months.

Remember Phil Ferrarotto who we met earlier in the season? After 18 years of multiple cancers and having had just about every organ you can think of removed, Phil's last weeks were spent being injected with Fentanyl, a powerful painkiller, but as his daughter Katie explained:

**Katie Harley:** There were days when it wasn't killing his pain. Sometimes it would space him out, sometimes it would make him sick, and it wasn't keeping him comfortable. No increases of any of the pain meds was doing anything different. This was complete agony, and it was with every breath. To breathe hurt, to swallow hurt.

**Andrew:** Phil's uncontrollable pain was a 'refractory symptom.' And the second limitation of terminal sedation?

**Roger Hunt:** Whether it is used or not depends on the doctor: what the doctor's world view is, whether the doctor believes it's going to hasten the person's death or not.

**Andrew:** This is Dr Roger Hunt, a pioneer of palliative care in South Australia. When he started working in this field 36 years ago, Roger had no fixed position on assisted dying, but experience has shown him the need for it because some suffering can only be relieved by death.

**Roger Hunt:** Yes, I think that is true. And that is why loved ones say to people, 'It's a merciful release when the person dies because all that was left was the shell of a person, and death is the final release from that suffering.'

**Andrew:** The use of terminal sedation is guided by a concept called the Doctrine of Double Effect.

**Roger Hunt:** It was a Catholic theologian, Thomas Aquinas, 800 years ago, that developed it.

**Andrew:** It says that if you are treating someone who is dying, it is moral to give them medication which may have the unintended effect of hastening death, but only if your intention is to ease suffering. It is not moral to give medication with the intention of hastening death – even if only death will end their suffering, and even if such help is requested.

**Roger Hunt:** The Church says it's okay if my intention is to just relieve suffering. And that's what I think I'm doing. So, I'm happy to administer the terminal sedation

**Andrew:** If that sounds like a fine line to tread, it is. And Dr Hunt believes it can create a power imbalance in end-of-life care.

**Roger Hunt:** This ethical principle focuses entirely on the clinician and what's in the clinician's mind. Patient autonomy, or what the family thinks, doesn't come into it. It encourages a kind of paternalism, that the only important thing is what the doctor thinks.

**Andrew:** Different doctors, of course, think different things. Take, for example, New South Wales doctor, Catherine Lennon, founder of non-profit Catholic organisation Matercare Australia, which encourages medical professionals to act as 'prophetic witnesses' by 'reflecting on the teaching and practice of The Gospel.' She doesn't believe in terminal sedation at all.

In a 2004 *Sydney Morning Herald* article, she was quoted describing it as a 'cruel way to die,' one that was only practised by 'unethical doctors.' She even warns her patients, 'Watch out for relatives in hospital to make sure they are still being given food and fluids.' In other words, make sure they die a natural death.

Within palliative care, argument has raged for years over whether or not terminal sedation actually does hasten death. But just the possibility that it might can influence end-of-life decisions.

**Roger Hunt:** I think that sets up a whole culture within Catholic hospices and more generally, that makes it difficult for some people working in palliative care. If they think that they may be, you know, hastening things along, they're looking over their shoulder and thinking, 'Oh, I've got all these eyes looking at me, nurses or colleagues complaining that you're too heavy with the drugs. "What are you trying to do? Are you trying to hasten the dying?"' If they think that this is a slow euthanasia, they'll shy away from it if that Catholic and religious influence bears upon them.

**Andrew:** What can this mean if it is you who is dying? In order to avoid accusations of intending to hasten death, the delivery of sedatives and analgesics is slowly increased, which means that control of your pain and suffering may take days to achieve. As nutrition is simultaneously withheld, it can take up to two weeks to die.

Dr Hunt acknowledges that failure to adequately sedate patients is not restricted to faith-based institutions.

**Roger Hunt:** It could happen anywhere where paternalism trumps good communication and consensus about what's best.

**Andrew:** A problem not just for patients, but also, he believes, for his profession.

**Roger Hunt:** The reluctance to... to use sedation when it's clearly needed is something that palliative care needs to address. And the fact that some practitioners claim they rarely or never use it is a cause for concern.

**Andrew:** But, like everything to do with the politics of dying, this is not a black and white question.

**Roger Hunt:** I've worked with quite religious colleagues who were very quick to administer bigger doses of morphine, for example, than I would have used in the same situation. And I've worked in Catholic hospices where continuous sedation is administered without any questioning by powers-that-be.

**Andrew:** The uncertainty surrounding terminal sedation, whose use is unregulated, leaves many who are dying at the mercy of how doctors interpret an 800-year-old doctrine. In the words of the founding president of Palliative Care Western Australia, Clive Deverall, here read by an actor:

**Clive Deverall:** Every day, in different settings, terminally ill patients – most with advanced malignancies and uncontrolled symptoms – are terminally sedated. Excellent. But that is the Lotto Life: the patient has to be lucky enough to find a doctor willing to help.

**Andrew:** So, what's it like when Lotto Life gives you the wrong doctor?

*[PENSIVE MUSIC]*

**Andrew:** Jan and her husband Steve had loved each other for a long, long time.

**Jan:** I was 14, he was 16, and we were both pretty shy, and we were both still kids as far as our families were concerned, and we fell in love.

**Andrew:** Nearly half a century later, they were still in love. Then, only days after his 65<sup>th</sup> birthday, Steve got terrible news.

**Jan:** He had stage four cancer. It was everywhere, all through his bones, from his cheekbones, through his hips, his spine, his knees, thighs... just... the scans that just looked like someone had blasted him with a shotgun, you know. There was just black holes through his whole body.

**Andrew:** Steve was from the school of 'what doesn't kill you makes you stronger.'

**Jan:** He loved life and he elected to fight. He really was going to give it a red hot go and try anything, and he did. He kept having chemotherapy, radiation, everything that we could do. The pain was intractable, always.

**Andrew:** This went on for twenty-one months.

**Jan:** I really don't know how he did it, and all the time hoping that the next round of this or the immunotherapy, or the next thing, would be the one that was going to save him, because he wasn't giving up. He wanted to live.

**Andrew:** But the immunotherapy drug, Steve's last, best hope, proved futile.

**Jan:** It hadn't stopped the progression of the tumours through the bones, and Steve, he said to me, 'Honey, I'm done,' and I knew he was. And we walked past a doctor, a specialist that we knew, and he said, 'Ah, the inseparable couple. How are you?' And we said, 'Oh, not so good today.'

**Andrew:** Steve wanted to die at home, but agreed to move into hospital so his pain could be better managed. In 2017, he entered a Perth palliative care facility, described on their website as 'a ministry of the Catholic Church,' continuing 'the healing mission of Jesus.' Jan set up a camp bed next to his. Then Steve called in the doctor and the pain specialist.

**Jan:** He said, 'This is what I want. I want to see my friends over, like, a day and say goodbye. I want to see my extended family, and then I just – with Jan – I just want to go to sleep until I die, so I just want to be put into a deep... like, I don't want to have pain. I just want no more pain, because this is just so bad.' What he called 'the good part,' like his reward for fighting so hard and being so brave was to be able to have that peaceful sleep, and then eventually pass away. And they said, 'Okay, yep, that's the plan.'

**Andrew:** Six days after entering the facility, Steve made his farewells of friends and extended family. Then he waited for the 'good part': to be sedated to the point his pain would stop.

**Jan:** We absolutely trusted that what he'd asked for would be what happened, only it didn't happen. He was lying there in absolute agony, and he was crying.

**Andrew:** For nearly two weeks, this continued.

**Jan:** We were both utterly bewildered because we thought that he would be in a peaceful sleep until death came, and this was about as far from that as you can imagine. He was still being actively nursed, he was still being actively washed, he was crying out in pain. His lungs must have been full of, like, this thick yellow liquid, and it would come up until it was, like, coming out of his mouth and they would sit him up and as it sort of trickled out of his mouth, I would scoop as much as I could out and away, and this would just go on for hours until the level dropped enough that he could then be laid back on his back. I can't overstate his pain. I just cannot overstate what it's like, and I can't overstate our belief that it was

going to be controlled and it wasn't.

He was desperate. He said to me, 'Get me out of here. I want to go home. Get me out of here.'

**Andrew:** Traumatized, Jan went into the corridor and stopped a nurse.

**Jan:** I said, 'Steve wants to come home and take every tablet in the place. He just can't stand any more of this.' She said to me, 'Your doctor,' and she named him, 'doesn't believe in this drug,' or 'the use of this drug,' and she wasn't even talking about an assisted dying drug. She was talking about a drug that's legal now, but he didn't believe in its use. And I said to her, 'But Steve is dying anyway, and he just wants to die without pain, and he is not asking to have his death brought forward, but he would have asked for that, if he could have.'

**Andrew:** Had Steve that legal choice, Jan knows what he would have done.

**Jan:** He absolutely would have said, 'Let's go home, let's all be together, let's say our goodbyes, and then my pain will end and yours will begin.'

**Andrew:** The nurse listened closely to Jan.

**Jan:** She said, 'There is another drug that Steve hasn't had yet that might achieve that level of sedation that he's looking for to control his pain.' She said, 'Leave it with me,' and I did. And he got the drug the next day. He went into a deep, deep sleep. It was exactly like he wanted it to be.

**Andrew:** For two weeks, Steve had suffered unnecessarily.

**Jan:** This profoundly shocked me. Steve very clearly asked for what he wanted and repeated it, and had been told, 'We will make you comfortable.' And he believed that's what he was going to get.

**Andrew:** In every sense, both he and Jan were robbed of a loving ending to their shared life.

**Jan:** I had my stretcher set up beside him so that I could hold his hand, and I fell asleep, and when I woke up – and he was sort of curled up – and he just looked so small. *[VOICE BREAKING]* And his hands were kind of – he had beautiful hands. He had big, solid, muscular hands and arms, and they just looked like... and he... he had died, and I wasn't there with him, and I promised him I would be, *[SOBS]* and that really eats at me. So – and... sorry. *[STRUGGLES TO CONTROL TEARS]* Yeah, I really – I loved him very, very much, and he loved me. We saw everything through together. We should have been able to see his death through, and he was on his own, dying, so I just don't know how it was for him, but at least it was ended. At least it was done.

*[SAD MUSIC]*

**Andrew:** For all Steve's suffering, Jan's admiration for those who care for the dying remains undiminished.

**Jan:** I have the greatest respect for people who work in palliative care, the doctors and the nurses, and the specialists – everyone. They do an amazing job.

**Andrew:** Her complaint lies with a system – and a law – which enabled Steve's death to be dictated on someone else's terms.

**Jan:** You might think you're going in and you're going to have great palliative care, but it is an absolute lottery. It is going to depend on who you get, on what their beliefs are. You are disempowered, totally disempowered. You can scream the place down if you want but, you know, if they think that you're comfortable, you know, that's it.

[SILENCE]

**Andrew:** The facility where Steve died lists amongst its values: *'Compassion – feeling with others and striving to understand their lives, experiences, discomfort, and suffering'*

[PENSIVE MUSIC]

**Andrew:** Over the last decade, hundreds of accounts of painful and undignified deaths have been put on Australia's public record, many at parliamentary inquiries. The reasons for these deaths, in hospitals of all kinds, were found by these inquiries to be multiple: doctors hesitant to give too much pain relief, afraid of accusations they were hastening death; patients given futile treatment long after it was doing any good; palliative care's limitations in dealing with all suffering, despite its many benefits; and laws which meant that, for some, death could only be slow and, often, traumatic.

Two other reasons, however, were rarely discussed.

One: a widely used medical practice known as the Doctrine of Double Effect, which focuses on what the doctor thinks rather than what the patient wants.

Two: the religious elephant in the room: a moral code which effectively disenfranchises people from deciding about their own lives; one which, as Professor Broom observed, instils its own values around dying.

The word 'palliative' comes from the Latin 'palliare,' meaning 'to cloak'. Each time assisted dying is debated in Australia, doctors and institutions of faith argue that it should not be legal until top-class palliative care is available to everyone.

It's an argument cloaking a deeper truth: no amount of palliative care is going to give dying people control inside a system based on the belief that life is sacred and dying is a matter for God.



*[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](http://gogentleaustralia.org.au).

In the next episode of Better Off Dead: if the first year of Victoria's law has shown one thing, it's that the people who've requested help to die know exactly what they're doing.

**Phillip Parente:** It takes a lot of courage. Patients are very clear when they request it.

**Andrew:** But that's not how some who believe in life as God's gift portray them.

**Archbishop Coleridge:** Very often, people who want to end their own life are suffering from depression, loneliness; that sense of being a burden.

**Andrew:** Some even suggest that these requests are the sign of an unwell mind requiring treatment.

**David Kissane:** Demoralised people can be actively suicidal and that interferes with their decision-making capacity. Mental illness, in other words.

**Andrew:** The Vatican says that any request for assisted dying is not to be seen as genuine. Now, some of the most senior voices in Australian palliative care are pushing back.

**Roger Hunt:** Many people in that situation are very rational. They don't have a psychiatric condition.

**Molly Carlile:** I don't think anyone's got a right to say to somebody else, 'You can't make a decision for yourself.'

**Michael Ashby:** It's not up to me to tell other people how they should die.

*[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](http://wheelercentre.com/betteroffdead) to learn more about the people and ideas from each episode.

*['LOYDIE'S ANGEL' CONTINUES]*