

Better Off Dead

Transcript for season 2, episode 10: We, Who Walk Towards Death

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: This episode of Better Off Dead is the second 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'll 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?'

Jaala Pulford: I love palliative care. It is a ray of sunshine on the darkest, hardest days.

Andrew: One of the most heartfelt tributes to palliative care I have ever heard came during Victoria's parliamentary debate about assisted dying.

Jaala Pulford: I think of the gap between terminal diagnosis and death as a journey, and palliative care professionals as the guides, someone gently taking you by the hand and providing physical, emotional and spiritual guidance and care.

Andrew: The speaker was Jaala Pulford, then-Minister for Agriculture. As she spoke, the normally rowdy chamber fell silent.

Jaala Pulford: I never really could work out where the job of a palliative care worker starts and ends.

Andrew: Everyone listening knew that Jaala was speaking from the deepest part of her heart. Three years earlier, she had sat in palliative care as her 14-year-old daughter, Sinead, was dying of cancer.

Jaala Pulford: Palliative care staff I have encountered have made cups of tea; passed the tissues; administered the medicines; calmly given instructions over the phone; provided advice on managing drama in the broader family; encouraged respite breaks; and talked and talked and talked about illness, dying, and death with great clarity and authority.

Andrew: As her tribute to palliative care unfolded, tears flowed around the chamber. When she finished, politicians from all parties embraced her. It was a raw reminder of how death can bring us together, just as it can bring us undone.

Death. Most of us recoil from it. Yet, every day, those who work in palliative care look it squarely in the eye.

Who does that? Who are these men and women who choose to walk towards death?

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

[OPENING TITLES. VOICES OVERLAPPING]

Molly Carlile: The thing I loved about it was you could speak from the heart. And if you spoke from the heart as a clinician, you would never make a mistake.

Andrew: Meet Molly Carlile AM.

Molly Carlile: My background's predominantly in palliative and end-of-life care for years and years and years.

Andrew: Since 1988, in fact.

Molly Carlile: When it wasn't even recognised as a specialty.

Andrew: Now a senior palliative care leader and member of Victoria's Voluntary Assisted Dying Review Board, Molly doesn't just look death in the eye; she helps others do that too.

Molly Carlile: When people have been sick for a long time, they go and have a million tests, and then finally they get a diagnosis, and it may be a horrible diagnosis. But they say, 'At least now I know what I've got to deal with.' And I think that's the beauty of palliative care. If we can be that honest voice for people that supports them in being able to make informed choices about what they do in their last days, we're doing a good thing.

Andrew: It's not always an easy conversation to have.

Molly Carlile: I can tell you a story of a very good friend of mine whose mum I looked after, and her mother said to me, 'Molly is this it? Am I dying now?' And I said, 'Yes, you are. But you know, we can do a whole lot.' Anyway, her whole family came and saw me. 'How dare you tell Mum she was dying?' It really caused a rift. And then, about eight years later, this lovely friend of mine got diagnosed with breast cancer, and I went down, and I slept by her bed over the last couple of days on a mattress. And one night, she opened her eyes, and she was holding my hand and she said, 'I understand, Mol, why you had to tell Mum. I understand.'

[GENTLE MUSIC]

Greg Mewett: Hi, I'm Dr Greg Mewett and I'm a palliative care physician in Ballarat, Central Victoria.

Andrew: For Greg Mewett, the path to palliative care began with his own family.

Greg Mewett: My mother died of metastatic breast cancer when I was just entering fourth year medicine at Melbourne Uni, and it was clear that she didn't get adequate pain control. And I kept thinking, 'There must be something better you can do than this.'

Andrew: Then, a lecture, and a lightbulb moment.

Greg Mewett: A guy at the Royal Melbourne who talked about how to give adequate pain relief, So, over the last 15 years of my 22 years in general practice, I just got more involved in palliative care in Bendigo, and then I eventually decided I would jump ship and do the specialty training.

Andrew: That was 15 years ago. Today, Greg finds his work at Ballarat Health most rewarding when all the skills of his palliative care team are called into action.

Greg Mewett: When people come in really difficult and complex circumstances. They've got a lot of symptoms – physical, psychological, psychosocial – and as a team we can bring to bear various things on that suffering, and to get someone who turns around says, two days later, 'My nausea, it's almost gone.' So, you get this immediate feedback, and you feel that sense of, 'Yeah, we can do something in a pretty shitty time of people's lives.'

Michael Ashby: I'm Michael Ashby. I'm a palliative care physician working in Hobart, Tasmania.

Andrew: Like Greg, it was a death in the family that set Michael on his path.

Michael Ashby: My father was killed in a road accident in France, and suddenly, my brother and I are at the age of 11 and eight, and our mum in her 30s, were cast into this journey of grief and loss. I look back and I can't help but feel that my whole journey into medicine and, ultimately, palliative care was probably driven by some complex and still difficult to understand personal motivations to confront death. It was almost like the arachnophobe

sticking his hand into the jar of spiders.

Andrew: UK-trained, Michael came to Melbourne to work at the Peter MacCallum Cancer Centre. Then, an ad in the paper seeking an inaugural director for Royal Adelaide Hospital's Mary Potter Hospice. To his surprise, he got the job.

Michael Ashby: At the time, there were just so few people who were willing and able to take up positions like that.

Andrew: The year was 1990. 30 years later, he's one of Australian palliative care's most respected voices. One-time national president of their peak body; now, as well as his work at Royal Hobart, he's Chair of medical ethics and death studies at the University of Tasmania. He, too, sees honesty as the core of the work.

Michael Ashby: it's a bit like reverse midwifery. You help people to acknowledge the realities of the situation and deal with them.

Andrew: Yet, for Michael, still that personal dance with death.

Michael Ashby: When I started off in 1989, it was all about something happening to other people. But now, when I go on ward rounds and I look at the person in the bed, and I think, 'Shit, that person's younger than me.'

Andrew: As we speak, Michael reveals that he has recently experienced his first knock on the door of mortality: tests suggesting the possibility of prostate cancer.

Michael Ashby: I was scared and apprehensive, and all of the things that I would expect somebody who'd just come from a job in banking or tree pruning.

Andrew: In a few days, he'll be going in for a colonoscopy.

Michael Ashby: Am I worried that the surgeon will walk in after and say, 'Well, actually, Michael, we've found rather nasty lesion in your descending colon?' Absolutely. Do I fear it? Absolutely, I do.

Andrew: Like most human beings, Michael is confronted, not just by death, but by what dying might mean.

Michael Ashby: 'Okay, Mister Omnipotent Palliative Care Doctor who is the midwife of other people's dying, what are you going to do with your own dying if you have full knowledge of it?' Will I be able to live up to the courage that I have sometimes confronted others with? And I think the answer, so far, is a resounding 'no.'

[PENSIVE MUSIC]

Andrew: To understand palliative care's mission – and why, in most parts of the world, it finds itself entrenched in opposition to assisted dying – it helps to understand its history.

First, two quick definitions. ‘Palliative care’ is a specialist type of treatment for people living with a terminal illness. It doesn’t aim to cure, but to relieve symptoms and help people live as well as they can while they die. It can be provided in an acute hospital, a person's home, or an aged care or residential facility, usually by a palliative care service. A ‘hospice’ is a place where palliative care is specifically provided. Here’s Molly Carlile:

Molly Carlile: Hospice happened in the 15th and 16th century, with nuns looking after dying people in monasteries.

Andrew: The term ‘hospice’ wasn’t coined until the 1800s by Mary Aitken, a nun living in Dublin who gave over her home to the sick and dying. She called it a ‘hospice’ because she saw it as a way station to the afterlife.

Molly Carlile: And our modern version of palliative care has evolved with that ethos. A lot of people who worked in in the very early days did come from that Catholic and Anglican framework, because the dying were seen as being unable to be physically rescued, but able to be spiritually saved.

Andrew: The first modern hospice was founded by a devoutly Anglican nurse, Cicely Saunders. After the near-simultaneous deaths of her husband and father, Saunders, in a state of ‘pathological grief’, felt a calling from God. Seeing no special place in the medical system for the dying – and realising that they needed care beyond the purely medical – she established the world’s first purpose-built hospice: St Christopher’s in London, in 1967. Her philosophy of palliative care was simply expressed:

Dame Cicely Saunders: You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.

Andrew: Sparked by her compassion and energy, palliative care has grown from a single London hospice to a worldwide specialty with strong government support. Its goal of providing holistic care for the terminally ill ranks it as one of the most important developments in modern medicine.

People who seek palliative care can be suffering from physical, spiritual, psychological, or social pain. Sometimes, it can be all these things, what Saunders called ‘total pain.’

To relieve such suffering – usually at a time of heightened emotions – sets those who work in palliative care unique challenges. Here’s Molly Carlile:

Molly Carlile: Anyone can give an injection, write a script, dress a wound; those things aren't hard. The hard things are listening to someone tell you how they had an affair when they were in their 20s, and they've never told their wife, and they're thinking about telling her now, and they're dying.

Andrew: The crisis faced by some as they reckon with their lives, and now their dying, is often described as ‘existential distress’. Michael Ashby explains:

Michael Ashby: There's the contents of one's life. And... and that's often messy. You don't suddenly acquire a new life, a new personality, new relationships. For so many of us there's separation, divorce, second families, complex relationships

Roger Hunt: It's often mixed up with other things, too, like confusion and delirium.

Andrew: This is Dr Roger Hunt: since 1984, one of South Australia's palliative care pioneers.

Roger Hunt: Anxiety and distress is very intense. The human being is a very complex and intertwined organism.

Andrew: Adding to this complexity, the reaction of families.

Michael Ashby: Families have an enormous – and at times adverse – effect on dealing with death and dying. One of the biggest obstacles is the baby boomer child who is disbelieving of what's happening. The hip fracture is just a bit of bad luck, dementia is a bit of memory failure. The baby boomers are resistant to the dying of their parents because they know they're next. They don't like it.

Roger Hunt: I remember one guy who's losing his mother with heart failure. And she was in her 90s and had multiple medical problems, and it's like, 'Well, why can't you give her a heart transplant?'

Andrew: A family's distress can be part of a dying person's suffering. As Dr Libby Smales, a palliative care physician I met in New Zealand, put it: 'The dying are witnesses to their family's pain, just as the family are witnesses to theirs.'

Molly Carlile: If someone has psychological, emotional or spiritual pain, their physical pain will be worse, no matter how much morphine you give them.

Andrew: And, sometimes, it's pain that simply can't be fixed.

Molly Carlile: It's horrible listening to someone who is spiritually or emotionally conflicted, or where social networks just disappeared, and they're trying to navigate all of that while they're physically deteriorating. And it's a hard thing to sit with because you can't fix it. I often have to stop myself saying something to make me feel better. That's not the answer. The answer is sitting in that space of discomfort and holding it, so that that person can move the way they need to move through it. Even if that means, sometimes, they're stuck there and just need to be held in that space. And I've always felt very strongly that that is our job.

Andrew: That, and to tell people the hardest thing: that death is close.

Michael Ashby: Probably the biggest role that we fulfil is calling it. And what happens on the other side is there is nearly always a greater peacefulness, and also an honesty that you no longer have doctors, nurses, relatives, friends, and the patient all living in different time zones with regard to what they understand to be going on. I've had very few people say to

me that I called it too early, but I've had so many people say, 'Well, if only I'd known, I would have stayed at the hospital.' That, I've heard a lot.

Andrew: Some never reconcile themselves to dying. While for others...

Roger Hunt: Most people do come to terms with their mortality. They realise they're going to die, and very often people are saying, 'I just wish it would hurry up and happen.'

Andrew: This, too, can be part of existential suffering. The wait for the inevitable as illness drags you further from the life you knew. Here's Greg Mewett:

Greg Mewett: It's about their existence. 'Is this existence acceptable to me? No. Can I do anything about it? I'll seek help and see what happens. Is it helping? No.'

[SAD MUSIC]

Andrew: More than half of Australia's palliative care is supplied by the Catholic Church. The Vatican says that, if you are a Christian healer, to help someone die means to 'help him to live intensely the final experience of his life.' It encourages doctors of faith to announce the Gospel to the dying. Doctors such as Andrew Sloane, now a Baptist Minister, also an opponent of VAD, here addressing the Christian Medical and Dental Fellowship of Australia in 2019:

Andrew Sloane: Over the years I've realised that when palliative care is prayerfully applied in a Christian context, God provides opportunities for ministry.

Andrew: The Church sees dying as an important time for spiritual growth. Here's how Catholic Health Australia's Code of Ethical Standards puts it:

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: The idea that suffering can have redemptive value was explained to the ABC in 2011 by Sydney's Catholic Archbishop, the Reverend Anthony Fisher.

Anthony Fisher: Theological thought here is that sometimes suffering can make something greater of us, but depending on how we suffer, the attitude with which we suffer. And the thought is, for Christians, by uniting that suffering with the suffering of Christ, that it's part of building up their own virtue, their own contribution to the world. That it's not completely meaningless.

Andrew: Finding meaning in suffering exists as an idea within medicine, too. Here's palliative care physician, also committed anti-VAD campaigner, 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: And here are the words of Father John Flader, published in The Catholic Weekly in October 2020, offering advice to a palliative care nurse wanting to know how to defend The Church's teaching on euthanasia.

John Flader: When a person is suffering, they may think a good God wouldn't want them to suffer like this, and they may ask for their life to be ended. But, for all we know, when their earthly suffering has ended, they may very well now be suffering far more in purgatory. God may have disposed that they should suffer a little longer on earth in order to go straight to heaven when they died. God knows what is best. Let us trust him.

Andrew: It is not that any medical professional holding these kinds of beliefs wishes a person to suffer; indeed, their very work is aimed at the relief of pain and suffering. But because the deeply faithful see dying as such an important time for spiritual and personal growth – one, perhaps, of ministry where the gospel may be preached – the thought that this may be short-circuited by someone using a secular Assisted Dying law in order to take control of the end of their life can be, quite literally, an affront to their universe.

In his 2020 Homily to the Catholic Archdiocese of Townsville on 'No Euthanasia Sunday', Bishop Timothy Harris put it plainly:

Tim Harris: We are created in God's likeness and image, and God alone has the last word in our lives.

Andrew: With its deep Christian roots and dominated, as it is, by the Catholic Church, palliative care in Australia, for many years, actively opposed attempts to legalise assisted dying. One of those who joined their chorus of opposition was Molly Carlile.

Molly Carlile: I had this firm belief in what we could do to ease people's suffering,

Andrew: Molly's family is Catholic to its bootstraps.

Molly Carlile: I come from a big Irish, Scottish, Catholic family on both sides. I've got three uncles who are priests, a cousin who's a priest. I've got a cousin who's a nun.

Andrew: She didn't just observe her Catholic faith; she lived it.

Molly Carlile: I used to be a special minister. I used to take communion to the old people's home. I love the welfare, social justice, care, compassion part of the Catholic ethos.

Andrew: And she trained for palliative care nursing in a Catholic hospital.

Molly Carlile: Sister Elizabeth McCray, I still think about her all the time. She was a beautiful woman. She was so wise.

Andrew: Like many in palliative care, Molly made her opposition to assisted dying public.

Andrew: This is something you wrote back in 2015: 'I've found that if we can address these elements of total suffering – physical, emotional, psychological, spiritual, social and cultural – effectively, often the whole issue of euthanasia becomes irrelevant.' Can you explain that to me?

Molly Carlile: Well, I've moved a fair way since then, Andrew, I've got to say.

Andrew: Okay, well, take me back to where you were then and why you thought that, and then let's talk about why you've moved.

Molly Carlile: So, I guess because I was involved in palliative care from early days, and I firmly believed, having looked after a lot of dying people, that a lot of the time the reason that they asked to have their life ended – and people had asked me – was because we weren't doing our job properly. So, okay, so what have we missed? Is it physical pain? Is it psychological pain? Is it spiritual pain? And unless you deal with those things early in the process, there's no point in saying to someone while they're actively dying, 'Is there something on your mind you need to talk about?' The opportunity is gone. And I've always worked from the theory that we needed to be in there really early and deal with the whole person in order to avoid that level of despair that required someone to think their only option was voluntary assisted dying. And that was my view.

Andrew: So, what started you changing your view?

Molly Carlile: So, it's very interesting, what started me changing my view, because I've got to say, very honestly – am I allowed to say a rude word?

Andrew: Of course.

Molly Carlile: I was really pissed off with you, majorly!

Andrew Denton: I know.

Andrew: When I first started speaking about this publicly back in 2016, Molly wrote an article objecting to my 'hijacking' of the conversation about end-of-life care, by giving my, quote, 'celebrity endorsement' to assisted dying.

Molly Carlile: I thought, 'What the hell does he know? He's not, you know...' And then I started to do a bit of self-reflection, and I thought, 'Why am I so angry about this?' And I realised that it was me feeling like people who were pro-VAD were actually critical of the job we were doing in palliative care. So, I went back, looking at what are the things that are triggering me here, and why am I taking this as a personal affront?

Andrew: Over time, Molly's thinking shifted.

Molly Carlile: The more I read, the more I thought, the more I talked to people. And the bottom line for me is: you can choose whether you want to stop having chemo or stop having radiotherapy, or don't have surgery or, you know, anything that you consider as futile treatment. You can say, 'I don't want to have that.' And we allow that. In fact, we very much push the idea that the acute environment is far more likely to impose futile care onto people, and we are the defenders of those people. So how can we say that, and in the same breath, say, 'Yes, you can make your choices, so long as it's not Voluntary Assisted Dying, because you don't have that right?' It was hypocrisy, as far as I could see. You can't say you're providing person-led care if you only do it with the things you agree with.

Andrew: In the pitched battle, back in 2017, to persuade MPs either to support or reject assisted dying, almost no-one from palliative care in Victoria spoke in favour. A rare exception was Greg Mewett.

Greg Mewett: In my naive younger days, Andrew, I used to think that if you had good palliative care, you shouldn't need assisted dying, and that's a view that still persists to this day, unfortunately. But it came as more experience and more time spent with people in these terrible times of their life. I came to realise, 'Well, actually, for some people, that's an important option that they need to have, and that it doesn't necessarily undermine my work as a palliative care doctor.'

Andrew: Greg's peak professional body, Palliative Care Victoria, warned the government in its submission to their 2016 end-of-life inquiry that, should it be legalised, assisted dying must be:

Male voice: Strictly separated from all health care services. It is not healthcare treatment and should not be undertaken by health professionals

Andrew: Greg saw it differently.

Greg Mewett: I didn't see it as one against the other. I viewed it as another choice that people may make as they come towards the end of their life. No different to someone saying, 'I don't want to be on this ventilator for my motor neurone disease anymore.' So, people are allowed to legally do that. They can't legally say, 'I want to stop my existential suffering from wasting away with a horrible head and neck cancer,' for example.

Andrew: The reaction from his peers was mixed.

Greg Mewett: And I got a bit of hostility: 'You're Judas.' but I also got some feedback from people who said, 'Good on you.' They weren't prepared to put their silly head above the parapet, but I did.

Andrew: For Greg, the issue was not about how doctors felt or what they may believe.

Greg Mewett: From a palliative care point of view, it's not for me to say how much someone's suffering and whether we can do more. It's all very well to have religious or

quasi-religious views about suffering, but it should be up to individuals to be able to set the limit of suffering when all else has failed.

[PENSIVE MUSIC]

Andrew: In the fight to legalise assisted dying in Australia, one argument in particular has been persuasive in getting politicians to vote ‘no’: that the solution to bad deaths is not VAD but giving more resources to palliative care.

Those doing the persuading are mostly doctors, often palliative care doctors, many of whom share The Church’s worldview that ‘God alone has the last word in our lives.’ Their authority as ‘experts on the care of the dying’ gives them a powerful voice in the debate.

Their argument – that palliative care has all the answers needed to stop bad deaths happening – has had real political consequence. In 2016, representatives of Palliative Care South Australia briefed MPs ahead of the next day’s debate to legalise assisted dying.

According to notes made by a staffer who attended the meeting on behalf of Kelly Vincent MLC, one MP told the palliative care delegation:

Female voice: It has been put to me that some people can’t be treated with palliative care.

Andrew: To which they responded:

Male voice: What we can’t deal with is the existential distress. From the symptom perspective, with palliative sedation as the fall back, we can control everything.

Andrew: I was in the Chamber late the next night as the tied vote was broken by Speaker of the House and committed Christian, Michael Atkinson. This was the 15th time South Australia’s parliament had debated – and voted down – assisted dying.

The MP who dramatically crossed the floor at the last minute to tie the vote was then Attorney-General, John Rau. Rau had been at the previous day’s briefing by Palliative Care South Australia. Speaking to Adelaide newspaper *InDaily* after the vote, he gave as his reason:

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

Andrew: The same tactic was used in Victoria in 2017. On the day the parliamentary debate began, a group of senior physicians addressed MPs at Parliament House. Amongst them, Dr Natasha Michael, who runs palliative care at Melbourne’s Cabrini Hospital, part of Catholic Health. A committed Catholic, in 2016 Dr Michael addressed the Mary McKillop Centre in Adelaide on the theme of ‘mercy’ as a central element of the Catholic faith.

A prominent voice in the media against assisted dying, in 2012, she appeared on Channel Seven’s *Sunrise* to debate with GP, Dr David Swanton.

Andrew O' Keefe: Dr Michael, why shouldn't we legalise euthanasia?

Natasha Michael: I teach medical students from The University of Melbourne and 90% of them would support euthanasia. They then spend a week with me, on wards where I care for 800 to 1000 patients a year with life-limiting illnesses, some with very difficult pain, some with intractable suffering. They watch how, with very meticulous and expert attention to detail, with very good analgesia, with excellent multi-disciplinary care, we provide extraordinary care in a very ordinary measure for these people. These people are discharged home. They live extremely good lives. Many of them return to work and return to families. And I ask them the question at the end of the week, when they have now experienced the context in which these decisions are made, 'Do you think we should legislate euthanasia? Do you see this intractable suffering that the media portrays out there, this unrelieved pain that supposedly many Australians suffer from?' The answer is 'no.'

Sam Armytage: Dr Swanton, yes, you've been shaking your head throughout that. What do you say to those claims? Do many people in palliative care go home?

David Swanton: Well, palliative care is very important, and we should spend more money on it. However, there are many cases where palliative care does not work, and Dr Michael should admit to that.

Andrew: Joining Dr Michael as part of the delegation addressing Victorian MPs in 2017 was Dr Stephen Parnis, former vice-president of The Australian Medical Association. For much of his career, Dr Parnis has been based at St Vincent's and Werribee Mercy Hospitals, whose stated Catholic mission is, 'Bringing God's mercy to those in need.' Here he is in 2018 giving an oration with Dr Michael to The Australian Catholic University, titled 'Widening the Doors of Hope.'

Parnis: As a doctor, I have the expertise to relieve suffering, to provide care and compassion, and thus enable a good death. I have an obligation to provide the best possible care and to walk with my patients and their loved ones.

Andrew: Like Dr Michael, Dr Parnis is also committed to his faith. In services at his church, he sometimes performs the roles of Commentator and Lector. In the Catholic Church, Lectors are 'Ministers of the Word,' charged with bringing the living Word of God to the liturgical assembly.

On the eve of Victoria's parliamentary debate, Dr Parnis and I were guests on Triple J radio's current affairs program *Hack*. I went first.

Sarah McVeigh: With you is Andrew Denton. You've travelled all around the country hearing people's stories for your podcast, *Better Off Dead*. What did that show you?

Andrew: Because of our existing laws, doctors feel constrained in the amount of pain relief they can give, or, because of their religious or moral beliefs, they will not hasten a patient's death. They will do so slowly, and our existing laws gives them the total power to do that,

which means that patients die in great pain.

Andrew: Next up was Dr Parnis.

Sarah McVeigh: Andrew Denton just made the assertion that this is really more about your religious beliefs. What do you say to that?

Steve Parnis: I say that's a bit of a cheap shot, actually. I think, let's focus on evidence.

Sarah McVeigh: Why do you oppose euthanasia?

Steve Parnis: Well, it's all presented as a choice but, at the moment, we don't have a real choice because the alternative, which is good – excellent – palliative care is not available as widely as it should be.

Andrew: Dr Parnis was asked if this lack of palliative care meant people who were suffering at the end of life should have no option.

Steve Parnis: No. What it means is that we need to understand why they're suffering, and we need to alleviate that suffering. And, when palliative care is done properly – and I've seen it, I've delivered it – the causes of suffering go away, and ...

Sarah McVeigh: But isn't it also true that, for some people, they don't?

Steve Parnis: Maybe a tiny proportion. I have to say that the proponents of this law absolutely exaggerate the numbers. And when palliative care is delivered properly, those sorts of horror deaths that some of the groups try and paint out need never occur.

Andrew: There it was again: the claim that palliative care had the answers to bad deaths. A claim that, like South Australia the year before, was to be repeated in the Victorian parliament by MPs opposed to assisted dying.

Male MP: Advocates say that palliative care cannot relieve pain and physical distress, but the experts tell us it can.

Male MP: A number of specialists in palliative care medicine have offered their advice to members of parliament. According to a senior professor of palliative medicine in this state, all pain can be addressed ultimately through palliative sedation.

Male MP: I was greatly comforted by a professor of palliative care who said, in this House just a couple of weeks ago, that palliative care can control all the pain and deliver relief until death inevitably knocks.

Andrew: It's difficult to know where those who argue that palliative care can address all end-of-life pain and deliver relief until death knocks are getting their information from. Despite Dr Michael's words on *Sunrise* in 2012:

Natasha Michael: Do you see this intractable suffering that the media portrays out there, this unrelieved pain that supposedly many Australians suffer from? The answer is 'no.'

Andrew: When she appeared in 2015 before the parliamentary inquiry that paved the way for Victoria's Assisted Dying law, Dr Michael conceded, 'I am not here to say that we are the answers to everything, because we are not.' She knew this to be true because, for some people, there are no answers to suffering other than for it to be over. People like Jane Morris's mother, Elizabeth, who was a patient of Dr Michael's at Cabrini.

Jane Morris: Motor neurone disease is indeed The Beast.

Andrew: This is Jane, a former nurse, speaking as part of a Go Gentle video presentation to Victorian MPs ahead of the Assisted Dying debate.

Jane Morris: Mum spent some time in palliative care. I can't speak highly enough about the care until it came to the stage where Mum was dying. We were guaranteed she'd be given analgesia and [PAUSE. DEEP BREATH. VOICE TREMBLES] and medication to relieve any anxiety, fear, or pain. But Mum was in the minority where none of this worked. Mum did experience pain. Mum did experience fear. It was obvious she was dying. Dying can be ugly, and to have this long, protracted death – for not only Mum, but for all of us – was absolutely horrendous.

Andrew: In a letter to Go Gentle, Jane added, 'Her last 24 hours were especially horrific. The cruelty of Mum's prolonged death was now evident in her beautiful face. Death can be black, and it can assault all senses. We did not want this to be a lasting memory of Mum for Dad, so we had Mum positioned facing away from him and turned the lights off. No-one, not even staff members, left her bedside unscathed.'

We wrote to Dr Michael, sending her Jane Morris's account of her mother's death and outlining claims made by her and others about palliative care, inviting her to make comment and, if appropriate, correct the record. She did not respond.

In recent years, hundreds of accounts like Jane's – of horror deaths Dr Parnis claims 'need never occur' – have been made public at, and accepted by, parliamentary inquiries into end-of-life care in Victoria, Western Australia, and Queensland.

Adding to these accounts, testimonies from palliative care doctors and nurses. One was Clive Deverall, the co-founder of Palliative Care Western Australia. In an email to Go Gentle in 2016, Clive wrote that "palliative care" has become a mantra chanted by palliative care advocates, and especially religious organisations opposing euthanasia.'

Here's Clive in 2017, speaking at a public forum in Perth in support of assisted dying:

Clive Deverall: I have seen with my own eyes and have talked to relatives of deceased patients who experienced and witnessed awful scenes, particularly the terrible sounds of people hallucinating, delirious, and in unremitting pain. And the fact is even admitted by Palliative Care Australia that a significant percentage of patients have symptoms that cannot be controlled. At professional meetings of palliative care associations, they often have on the agenda what are described as 'palliative care nightmares.'

Andrew: Palliative care's peak national body, Palliative Care Australia, warns that, 'while pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal care.' The author of those words was Michael Ashby. I asked him how they came to be written, and he took me back to the early 90s when he was inaugural director of palliative care at Royal Adelaide Hospital.

Michael Ashby: There's a wonderful administrator, Sister Christina, who did massive work on improving palliative care. And being very true to her Catholic faith, she went on radio, on talkback in Adelaide, and basically sold what was the party line at the time. Given how poor access to palliative care was, and how community understanding was, was kind of understandable. But she said, basically, 'If you're suffering and in pain, we can sort it out.' And poor Sister Christina got several fairly irate callers ringing in saying, 'Well, no,' you know, 'my mother was in palliative care. And, you know, all the pain didn't go away.' And so yes, palliative care has limitations. And I think it's incumbent upon our medical specialty to be honest with people that we'll try our best and we don't give up, but that we can't abolish all symptoms. We can't relieve all suffering.

Andrew: How does he feel when he hears doctors claim that palliative care can?

Michael Ashby: I find any assertions of that nature to be untrue. I think the overselling of the product is also unhelpful and disingenuous.

Andrew: Greg Mewett, too, struggles with these claims.

Greg Mewett: I've seen bad deaths and I've heard of bad deaths in specialist palliative care units. If people say, 'Oh, well just come over to us and everything'll be fine,' it's just rubbish. There are bad deaths in lots of different settings.

Andrew: And then there is empirical evidence collected every year from palliative care units around Australia by the Palliative Care Outcomes Collaboration, known as PCOC. As Dr Roger Hunt explains, data comes from patients, using a symptom assessments scale.

Roger Hunt: Zero being absent symptoms, ten being a very severe level of distress associated with symptoms.

Andrew: There are many symptoms that can cause suffering.

Roger Hunt: Difficulty sleeping, nausea, bowel problems, breathing, fatigue, pain.

Andrew: By way of example, I asked him to explain what just one of these symptoms – breathing – could mean.

Roger Hunt: The person is breathless, just lying on the bed despite oxygen, despite opioids. They can get panic attacks as the oxygen level drops. It's exhausting.

Andrew: Data is also collected from clinicians working in palliative care. Interestingly, Roger observes that patients tend to rate their suffering as being more severe than clinicians do.

Roger Hunt: Whether that is because clinicians are a little desensitized to what the patient might be experiencing, or feeling like the patient's symptoms are controlled better than what the patient feels they are, but that's a fairly consistent finding in the data.

Andrew: I asked Roger to look at the most recent PCOC data from 2020 to see what it revealed about difficulties in controlling end-of-life symptoms.

Roger Hunt: In 2020, the proportions of people having moderate to severe symptoms of pain and breathlessness – we're talking 15 to 20 per cent – and some of these patients having multiple concurrent symptoms.

Andrew: And on top of all this, the knowledge that what is happening to you is likely to keep happening to you for the rest of your life.

The challenges faced by those who work in palliative care, who choose to look death in the eye when most of us choose to look away, are unique and complex.

Roger Hunt: I think people are very forgiving of palliative care doctors and nurses, and in their efforts to make people comfortable, if they're not successful. If they're trying, if they're communicating well, if the person is still suffering, there is going to be some understanding and forgiveness that palliative care clinicians can't always do a perfect job in really difficult and trying circumstances.

Andrew: In Australia we are fortunate. Palliative care has existed here for 45 years and is ranked second in the world, behind only the UK. For the vast majority of us, should we need it, the multifaceted care it offers will help ease our dying.

Yet even should we need it, we may not want it – a point often overlooked in this debate. Like every other medical treatment in Australia, palliative care is not compulsory. It is our legal right to say 'no.'

Everyone I've spoken to while making this series – families of those who've chosen VAD; doctors who've helped them; pharmacists who've delivered the life-ending medication; and people who are dying and who have the medication standing by – all have seen the benefits that palliative care brings. Almost all the 124 people who used Victoria's law in its first year received palliative care treatment, some for extended periods of time. But for all the help that it offered, for these people, it wasn't enough, and they invoked their legal right to take another path.

People like Lisa Hogg's mum, Margaret, who chose VAD as a release from the rare neurological disease that was killing her.

Lisa Hogg: She was virtually unable to do anything for herself. She was hoisted up in a sling with no pants on, being transferred from her chair into the toilet in front of staff. She was losing her ability to swallow, and she was starting to choke on her food, and particularly on drinks. She got to the stage, she couldn't even turn herself over in bed, so she couldn't make herself comfortable at any point. There was no drug, there was no treatment, there was no

surgery that would make her condition go away. There was nothing they could give her even to postpone the progression of her condition. In terms of palliative care, there was really nothing that they could offer her apart from, you know, occasional painkillers.

Andrew Denton: There were – and there still are – senior doctors who argue that, with proper palliative care, none of this suffering need ever happen.

Lisa Hogg: How do you equate that to someone whose illness has resulted in them losing all ability to carry out decisions they've made for themselves, whether it be to brush their teeth, or take a drink, or change the channel on the TV, or go out in the fresh air? Mum knew that this was going to get worse. Her suffering was suffering in... in the larger sense. there's no painkiller that would have taken that away. There's nothing they could have done.

[SOMBRE MUSIC]

Andrew: I've often wondered about doctors who argue that palliative care, when done properly or if properly resourced, has the answers to all suffering.

For a long time, I saw this argument as being largely political. It's worked well for many years; why wouldn't you continue to use it? But, over time, I've come to understand it as something else: an expression of medicine's old operating principle 'doctor knows best.'

In any other profession, if there was the same volume of credible and harrowing complaints about the services being offered, as have been accepted by recent parliamentary inquiries into end-of-life care, you would expect that profession's governing bodies to be asking questions of itself and its practices. And if it didn't, perhaps a Royal Commission would.

But not doctors. Or, at least, not their peak governing body, The Australian Medical Association, which continues to stand foursquare against assisted dying, even though, in a 2016 poll of its members, almost 70% agreed that 'palliative care cannot adequately relieve the suffering of some patients.'

In the public square, of course, doctors have the whip hand. They have a union, and a powerful one at that. Patients do not. When was the last time you saw terminally ill people marching in the streets for their rights?

Now, in 2021, The AMA stands alone amongst Australia's peak medical bodies in its opposition to assisted dying. The others either support it or, representing the divergent views amongst their membership, have declared they are neutral on the matter. One of those is palliative care's peak body, Palliative Care Australia, who, in 2019, moved their position on assisted dying from 'opposed' to 'neutral,' saying that its legalisation was 'a matter for parliaments.'

Still, there are those who – like Cicely Saunders did – argue against assisted dying because they believe palliative care has all the answers. I put this to Molly Carlile.

Molly Carlile: That's what I would have told you six, seven years ago.

Andrew: Did you really believe that? You would have seen deaths, I imagine, within palliative care which were not good deaths.

Molly Carlile: I did, but I believed that terminal sedation was the answer to that. You know, 5% of people had intractable pain, and we... we manage that with terminal sedation.

Andrew: Terminal sedation: the use of powerful drugs to put someone into a coma until they die – palliative care’s answer to suffering that can no longer be controlled. But there’s a catch.

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.

[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: the end-of-life lottery. What can it mean to die in a system whose values you don't share?

Alex Broom: These organisations are often infused with ideologies around what dying should be and what it means.

Andrew: Why do people still suffer, even when there are drugs which could help them?

Shayne Higson: He said, 'I can only give her this amount and every 15 minutes. If I give her more, it might end it.'

Andrew: And what are the consequences of a law which gives all power to the doctor?

Jan Kelly: You are totally disempowered. You can scream the place down if you want, but if they think that you're comfortable, that's it.

[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]