

Better Off Dead

Transcript for season 2, episode 12: A Cry for Help

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 fourth of four offering 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]

Ron Fellows: My question is to Margaret. I'm 90 years of age. My wife is 81, and if the time comes where we can't take care of ourselves, we will look for some form of euthanasia.

Andrew: It's 2017 and a revealing exchange is about to take place on ABC TV's QandA between Catholic bioethicist, Margaret Somerville, and an elderly couple in the audience.

Margaret Somerville: Your death is... it's a social event. It affects your family, it affects your community, and if what we're doing is changing the law to allow this type of – putting it bluntly – killing, then it is a seismic shift in our values as a society.

Andrew: Ron's wife, Patricia, takes issue with this.

Patricia Fellows: It's not about killing anyone. I'm not asking Ron to kill me. I will do it myself, and Ron will do it himself. I don't know what you're on about, darling, about killing.

[AUDIENCE LAUGHTER AND APPLAUSE]

Patricia Fellows: That is definitely the wrong word to be using.

Margaret Somerville: But it's still killing yourself.

Patricia Fellows: Yes, but that's up to me.

Margaret Somerville: Yes, I know, but that's –

Patricia Fellows: And it's got nothing to do with the community, darling. It's to do with our family.

Margaret Somerville: How you die does have to do with the community.

Patricia Fellows: Bullshit.

[AUDIENCE LAUGHTER]

Andrew: It was a revelation, of sorts, of the existence of two parallel universes in Australia. The conservative Christian universe, which believes our lives and our deaths belong to God. The other universe, populated by the roughly 75% of Australians – including a majority of Christians – with a shared belief we should have some control over how we die. Two different, yet sincere, belief systems. Except, only one seeks to impose its beliefs on the other.

In this episode, how rational requests to die are characterised, instead, as a misguided cry for help from the emotionally vulnerable.

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

[OPENING TITLES. VOICES OVERLAPPING]

Andrew: In 2020, The Vatican released its latest encyclical on assisted dying and euthanasia. They called it *Samaritanus Bonus* – the Good Samaritan – and this is what it had to say about people who seek assistance to die:

Male voice: Experience confirms that the pleas of gravely ill people who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love.

Andrew: Requests for assistance to die are 'not to be understood as a true desire for euthanasia.' In other words, the people making them are somehow misguided.

This narrative of requests to die being, instead, a wayward 'cry for help' has been promoted by The Church and some fellow travellers in the medical professions. Here, for example, is palliative care doctor and committed Christian, Megan Best, addressing the Freedom for Faith Christian Think Tank in 2014.

Megan Best: When patients expressed their fears at the end of life, it was often misinterpreted by healthcare providers as a request for euthanasia, when it was really intended as a cry for help.

Andrew: And again, in 2019, speaking to the Christian Dental and Medical Fellowship of Australia.

Megan Best: One thing we know about euthanasia requests is that they're usually a cry for help. So, we need to find out what's behind that request and see what we can do about helping that person feel less despair in their situations.

Andrew: Psychiatry recognises that some terminally ill people do express a wish to die which may change over time. If you'd like to understand more about the careful ways in which Victorian doctors determine which requests to die are genuine and which suggest another kind of care, you may want to listen to episode seven, *The C Word*, which takes you through the assessment process in detail.

According to The Church's narrative, people who request a hastened death are likely to be demoralised; lonely; abandoned, struggling to find meaning in – or even giving up on – their lives. But, they say, with the right kind of love and care, these things can be addressed.

In a Q and A with the *Catholic Weekly* in 2014, Brisbane's Archbishop, Mark Coleridge, put it in a nutshell.

Mark Coleridge: Very often, people who want to end their own life are in fact suffering from a recognised or unrecognised depression or a sense of loneliness. They want to end the pain of loneliness by being assisted to take their own life. Or that sense of being a burden, that I am now useless. All of those things underlie the push for euthanasia, and it's those things that need to be treated.

Andrew: In this episode, we're going to look at how this picture of depressed people giving up on life contrasts with the view of many senior palliative care figures: that these requests for an end to their agony can be both considered and rational.

But first, let's hear directly what actually happened in the first year of Victoria's law. A weave of voices from carers, loved ones, and some of the 124 Victorians who actually accessed the law, starting with Jean and Michelle Caliste, whose son Robbie was dying of Motor Neurone Disease:

Jean Caliste: It was 24 seven. There was no getting away from it. When it grabs hold, you have no functions and you're really – literally – a prisoner in a body.

Andrew: Nicole and Jacqui's mother, Kerry Robertson, who had metastatic breast cancer:

Jacqui Hicks: She'd been on chemotherapy for a prolonged period of time. It wasn't working anymore.

Nicole Robertson: It wasn't just the pain. It was the nausea, the vomiting, not being able to keep anything down, losing drastic amounts of weight, having tremors...

Andrew: Deb's brother, Colin, metastatic bowel cancer:

Deb: He'd completely lost control over any part of his life. He couldn't feed himself and it just broke my heart to think of him, and that sense he must have had of powerlessness.

Andrew: Katie Harley's dad, Phil, multiple metastatic cancers:

Katie Harley: Towards the end, we had to syringe different medicines in and it wasn't killing his pain. It was just complete agony, and it was with every breath. To breathe hurt, to swallow hurt...

Andrew: Kristin Cornell's dad, Allan, Motor Neurone Disease:

Kristin Cornell: For Dad, it was all his limbs that went first, and the breathing and the swallowing was incredibly aggressive in the last two weeks. He was dying. He was suffering. He was begging me.

Andrew: Peter Jones, chronic obstructive airway disease:

Peter Jones: My lung physician said, 'Well, you don't need to do any more lung tests because there's nothing there to test.' It's like walking around with a straw in your mouth, trying to suck in enough air. There's no cure for it.

Andrew: Ron Poole, idiopathic pulmonary fibrosis:

Ron Poole: There's no cure for it. It's just the lungs are getting harder and harder and the capacity is getting less and less. It'll come to that stage where I won't be able to breathe properly by myself.

Andrew: Fiona McClure, metastatic cancer of the rectum and abdomen:

Fiona McClure: When you look at the scans and all the masses are growing, and it's moved into your lungs, then yes, you know that things aren't good. The best hospital, I think, in Australia has sent me home without further treatment. I think that says it all.

Andrew: And, finally, Lisa Hogg's mum, Margaret, dying of corticobasal syndrome, described here by her daughter.

Lisa Hogg: Your body starts to seize up one limb at a time. There was no drug, there was no treatment, there was no surgery that would make her condition go away.

Andrew: That these people's suffering was very real, and no longer meaningfully treatable, is beyond question. But the requests for assistance to die – were they genuine? Or were they, as The Church suggests, really a cry for help masking deeper problems? Let's hear now from some of those legally responsible for deciding whether these people were mentally competent when they made that request, starting with oncologist, Professor Phillip Parente, Director of Cancer Services at Eastern Health, Melbourne:

Phillip Parente: It takes a lot of courage, a lot of discussions with their partners and their children or their parents. Patients are very clear when they request it.

Andrew: GP, Dr John Stanton:

John Stanton: They're all people that have thought about it a lot. No one comes to this overnight.

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

Peter Lange: These are people who have control over their own lives, they always have.

Andrew: Retired Supreme Court Justice, Betty King. As chair of the Assisted Dying Review Board, she's looked closely at every individual case.

Betty King: It takes determination to take all of these steps. You have to deeply desire it to choose the path and to stay the path.

Andrew: And Professor Michael Dooley, head of the Voluntary Assisted Dying Statewide Pharmacy Service, whose team have delivered the life-ending medication to each of the 124 people:

Michael Dooley: They're at the end of a long journey and they're steely-eyed determined that they've got a choice. They know exactly what they're doing.

Andrew: Now let's go back to Archbishop Coleridge.

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

Andrew: The idea that a person will choose to die because they feel a burden is widely used as an argument against assisted dying. Here are the words, performed by an actor, of the founder of modern palliative care, devout Anglican, Dame Cicely Saunders, when she spoke to the BBC about assisted dying in 1995:

Cicely Saunders: The real problem is that if that was made possible by law, then it would pull the rug from under a whole lot of vulnerable people. 'I'm nothing now but a burden and I ought to opt out.'

Andrew: It's a claim I have heard repeated many times, and in many ways, over the last five years. First, at a Sydney Town Hall debate about assisted dying I attended in 2015. The speaker was Sydney's Catholic Archbishop, the Reverend Anthony Fisher.

Anthony Fisher: First, it's for those who judge their own lives to be too burdensome for them, but how quickly societies that go down that path start making the judgment that those lives are too burdensome for others.

Andrew: I heard it again, multiple times, in 2017, throughout Victoria's parliamentary debate about assisted dying.

Male MP: The overseas experience is that large numbers of people who participate in assisted suicide do so because they fear being a burden.

Andrew: And again in 2020 in a video targeted at Tasmanian MPs from the anti-VAD group Care Alliance.

Stephen Parnis: World over, the reason for people saying that they want to take their life is because they feel that they are a burden, and they don't want to be a burden any longer.

Andrew: It was not the first time I'd seen politicians targeted with the 'burden' argument. In 2018, as Western Australia's Parliament prepared to debate assisted dying, an ad produced by Sydney's Catholic Archdiocese went up on Reverend Fisher's Facebook page.

[HEART MONITOR BEEPS]

Andrew: The words – superimposed over a heartline monitor which flatlines – read:

Male voice: On June 19th, euthanasia and assisted suicide will begin in Victoria. How long will it take for Victoria to look like Oregon? In Oregon, patients requesting assisted suicide are asked about the reasons they want to die. 9 out of 10 say they are afraid of losing autonomy. 2 out of 3 say they are afraid of losing dignity. 1 in 2 say they fear being a burden on family and friends. Only a quarter mention pain or fear of pain as a reason for their decision.

[HEART MONITOR FLATLINES]

Andrew: Like much clever advertising, this cherrypicked information – data from the Oregon Department of Health – painted a picture that told the truth, but not the whole truth.

Yes, patients in Oregon expressed a range of concerns while dying, including fear of losing autonomy and dignity, as well as fear of being a burden. But these were part of a multiple-choice list of end-of-life concerns those accessing assisted dying were asked to complete. Often, people chose more than one. As it happens, fear of being a burden was well down the list, behind loss of autonomy, dignity, and enjoyment in life.

Yet in Oregon, these painful feelings do not make someone eligible for assisted dying. For that, there was just only one crucial requirement: that they were dying, and suffering as they died.

The same is true in Victoria, where the law is very clear: you have to be dying of a terminal illness, mentally competent, and capable of proving, multiple times, that your request for assistance to die is your own. Fear of being a burden does not – cannot ever – make you eligible.

There is no question that feeling like a burden can be a genuine concern of the terminally ill. Here's Professor Michael Ashby, Director of Palliative Care at Royal Hobart Hospital, and one of the most senior and respected voices in his field.

Michael Ashby: Do people who are sick, particularly at the end of their lives, feel a burden to others and to themselves? Yes, absolutely. It is a significant issue. Do I honestly think that the burden issue alone will say to people, 'Well, I really don't want to burden my children, so I'm going to call up Exit and get the drugs'? I really don't think so. I don't think this is the primary reason that people would want assistance to die.

Andrew: The idea of relieving another's burden sits powerfully within the Christian tradition. Christ preached about it in the gospels, and it remains one of the core values of palliative care today, reflected in their language of 'walking with' patients in their suffering. As Michael Ashby explains, there is often a need to validate people's fear of being a burden.

Michael Ashby: For a lot of families, particularly for children, the economics are going to be very difficult. So, what gets said is, 'Oh, you're of infinite value. We can support you. Your family will come. Never say you're not worth it. No.' And what happens is, I see the people shrinking, thinking, 'But they haven't heard me, this is a dignity issue for me. I need to be able to say that I don't want to burden my kids. That really – that is one of my values.'

Andrew: In fact, The Catholic Church itself recognises that being a burden on your family as you are dying can be a legitimate reason to want to end your suffering. In 2018, the United States Conference of Catholic Bishops published guidelines saying it's permitted to refuse life-saving medical treatment if, in the patient's judgement, it entails a, quote, 'excessive burden on the family or community.'

Why does The Church see being a burden on your family or society as an acceptable reason to refuse life-sustaining treatment, but not to request voluntary assisted dying? Because the Vatican says the first is legitimate, while the second? Let's go back to *Samaritanus Bonus*.

Male voice: Euthanasia is an intrinsically evil act, an act of homicide 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: The Vatican's missive goes on to explain that, even when painful, death is an important rite of passage. And that, with Christian love, the dark thoughts brought on by dying and suffering can be lifted.

Male voice: A sick person, surrounded by a loving human and Christian presence, can overcome all forms of depression and need not succumb to the anguish of loneliness and abandonment to suffering and death.

Andrew: ‘Depression,’ loneliness,’ ‘abandonment,’ ‘loss of meaning’ – all are used alongside the word ‘burden’ by those seeking to paint that picture of the vulnerable person misguidedly seeking help to die instead of being shown the love they need that will lift them up. Here’s Cabrini Hospital’s Head of Palliative Care, Associate Professor Natasha Michael – herself a committed Catholic – in a 2017 debate about assisted dying posted by the Catholic Archdiocese of Melbourne.

Natasha Michael: We know that depression, hopelessness, anxiety, people who have very little social support, people who are bedridden, people who have severe symptoms... Very importantly, people who lose a sense of meaning or purpose in their life, or loss of identity, an inability to see a future, have these thoughts.

Andrew: Answers to these thoughts come in the form of what The Vatican calls ‘human and supernatural warmth’: a loving Christian presence providing hope and meaning, even when all seems lost. Here, again, is Archbishop Coleridge.

Mark Coleridge: Someone who is dying can be surrounded by love. The loneliness doesn’t have to be there, nor does the depression, nor does that sense of being a burden. Life, even at its most fragile, remains a gift and a blessing. Allowing God to be God and life to be the gift and blessing that God wants it to be.

Andrew: Instilling hope and meaning at the end of life has been, for many years, a central focus of this man:

David Kissane: Its real importance, clinically, is in the recognition that people who become demoralised may go on to develop a desire to die, and that then becomes a very serious state of affairs.

Andrew: Demoralisation is the special subject of Emeritus Professor David Kissane, an academic psychiatrist and psycho-oncology researcher, formerly the Head of Psychiatry at Melbourne’s Monash University. He argues that a request to die is most likely due to demoralisation: a pathological mental disorder that is often marked by loss of meaning in a dying person’s life.

David Kissane: Engel called it the ‘giving up, given up’ syndrome. Others have called it ‘give-up-itis,’ or mental defeat.

Andrew: Professor Kissane is also Confrere Kissane, Procurator of the Subpriory of the Immaculate Conception, in the Catholic Order of the Knights of Malta.

David Kissane: In the name of the most Holy Trinity, in the name of the Blessed Virgin Mary, in the name of St John the Baptist, receive this sign in defence of the name of Christ.

[WOMAN SINGING MASS]

Andrew: The Order of the Knights of Malta, founded in the 11th century, cares for the poor and sick in more than 120 countries. And here Professor Kissane can be heard investing new 'Knights and Dames of Obedience' into the Order, in Brisbane, in 2017.

David Kissane: ... in the propagation of the Faith, and in the service of the poor and sick. We have given you this cross, that defending it, you may love it.

Andrew: Like all Knights of Malta, Confrere Kissane makes a 'continuous pledge' to defend his faith against the 'enemies of religion.' He is also Professor of Palliative Care Research at two of Australia's most respected Catholic institutions, Notre Dame University and St Vincent's hospital in Sydney. And few in the medical profession have been more politically active in Australia against assisted dying over the last two decades.

Between 1998 and 2020, he made five personal submissions, and co-signed another three, to parliamentary inquiries into assisted dying. In 2017, he wrote to Victorian MPs, urging them to make psychiatric examination mandatory for anyone accessing VAD. As well, ahead of the debates in Victoria and Western Australia, Professor Kissane was invited to make a PowerPoint presentation to MPs, where he focussed on mental health in general and demoralisation in particular.

In both those states, he also recorded a series of video messages, such as this one, put out by the Catholic Archdiocese of Melbourne.

David Kissane: I'm concerned that those with mental illness will, in fact, end up making use of this act. One's spent one's whole life trying to prevent suicide, and now government's bringing it in. How terrible for medicine and for society for that to be happening.

Andrew: For the record, VAD laws in Australia expressly exclude people on the grounds of mental illness alone. And, as you've heard throughout this series, at their very core is the fact you have to be mentally competent to access them.

In this 2019 video, promoted by The Catholic Archdiocese of Perth, Professor Kissane describes the signs of a person suffering demoralisation.

David Kissane: These are people who lose a sense of morale, of coping, and they start to view their predicament as helpless, hopeless. They feel trapped and stuck with an illness that they can't control, and they begin to say, 'Life's pointless, life lacks meaning, why go on?' And, in fact, suicidal thinking flows from there.

Andrew: He goes on to say that – when severe – demoralisation can bring into question a person's state of mind.

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

Andrew: Speaking that same year to various Compassionate Communities Committees in Tasmania, Professor Kissane said this altered state of mind raises doubts about whether any request for hastened death should be seen as genuine.

David Kissane: If you've decided that your life is pointless and meaningless and you want to make a choice for physician-assisted suicide, that mightn't be the choice you'd make if you weren't demoralised.

Andrew: According to Professor Kissane's research, one of the protections against demoralisation is a belief in something greater.

David Kissane: Good support protects against it, as does a resilient personality and somebody with strong religious beliefs.

Andrew: How can meaning be restored? Professor Kissane cites one approach.

David Kissane: In Melbourne, Carrie Lethborg, a social worker at St. Vincent's, has what she calls Meaning and Purpose, or MAP, therapy, where you create a roadmap of how you're going to have this meaning in your life, and what purpose you're going to lay down to live life out fully, and to make it of value and beautiful for you.

Andrew: He proposes that people showing signs of demoralisation, which may develop into a wish to die, be assessed on a scale.

David Kissane: If somebody says they're discouraged, we want the clinician to name that emotional state. 'Are you rating your low morale, your discouragement as a seven out of ten?' And we want you to empathise. 'That must be so hard for you, such a struggle. But I wonder if there's a resilient side to you. Is there a part of you that represents your strength, that can help you to restore that morale, to fight back and to do better?'

Andrew: The concept of demoralisation was first identified by American psychiatrist, Jerome D Frank, in his 1961 book Persuasion and Healing. For the last 20 years, Professor Kissane and others have been writing articles urging that it be added as a new category of mental disorder to the psychiatrist's bible, The Diagnostic and Statistical Manual of Mental Disorders, or DSM. Used globally as the handbook for diagnosing mental disorders, the DSM is produced by The American Psychiatry Association, based on advice from its Scientific Review Committee after input from hundreds of top clinicians, specialists, and researchers around the world. When the most recent DSM was published in 2013, it did not include Demoralisation Syndrome as a category.

Few would argue that many of the things Professor Kissane champions – appropriate counselling, emphasis on what is still good in life, and empathy – can be beneficial in care of the dying. Just as acceptance of the reality of dying, and the positive effect of providing control, are part of dying well.

That people may be depressed, demoralised, or suffering from existential distress as they die has been recognised as part of the human condition for centuries.

But medicalising what many see as a natural response to the approach of death and pathologising requests to die as a form of mental illness? About this, there is much debate.

Malcolm Parker: My name's Malcolm Parker, Emeritus Professor of Medical Ethics at The University of Queensland.

Andrew: Professor Malcolm Parker has looked at Professor Kissane's work on demoralisation over 20 years. He spoke to me in his own right, not as a spokesperson for the University.

Andrew: In your view, where does the value lie in Professor Kissane's work?

Malcolm Parker: I think that, up to a point, what he is attempting to do is to improve the quality of palliative care, improve the comfort of people in terminal illness situations, improve the education of physicians, doctors who undertake palliative care. So, part of Professor Kissane's agenda is to provide proper support to people going through this terrible phase. I don't have any particular problem with that. What I do have a problem with, though, was that demoralisation syndrome appeared to be being used as a vehicle for, in effect, outlawing as legitimate and as rational any request by a person in this kind of predicament to request assistance for dying.

Andrew: Professor Parker is concerned about the possible consequences of treating requests for assistance to die as a symptom of another illness.

Malcolm Parker: If you say that all and every request for assisted dying is a cry for help, then what you are effectively doing by saying that 'Here is a person who's got demoralisation syndrome, which we can treat,' and if the category of demoralisation could be recognised as a diagnostic category, then of course it's subject to treatment. I viewed this as potentially paternalistic. These are people who know that they are going to die within a very short time. They're experiencing very difficult symptoms. They have, in many cases, lost feelings of meaning and purpose, and this is where Professor Kissane and his colleagues come in and say, 'Well, we can help to restore those kinds of feelings.'

Andrew: He believes the medical community needs to be careful not to over-step its role when it comes to the end of a person's life.

Malcolm Parker: We need to be cautious and respect those feelings – helplessness, hopelessness, even meaninglessness – and not necessarily step in and impose treatment. There's a tendency for critics of voluntary assisted dying to say, 'This person thinks their life is no longer worth living.' But I think they missed the nuance here, that a person who requests assistance to die has come to a decision that their life, as it is, is no longer worth living, not that their life as a whole has not been worth living.

Andrew: That people can, and do, make rational requests to die is acknowledged by Palliative Care Australia, as by many in the medical community.

Malcolm Parker: There are studies which show that a significant percentage of psychiatrists believe that people in these situations can rationally request assistance to die, just as people in the removal of life-sustaining treatment can perfectly rationally request the removal of the treatment.

Andrew: Requesting removal of treatment in order to hasten death is legal in Australia. The process can be slow and, for some, psychologically painful. It is not considered to be suicide and is ethically accepted by faith-based institutions.

Though ethically accepting a choice is not the same as supporting it. Professor Parker's 85-year-old father, Brooke, was dying from cancer and chose to stop treatment, including eating and drinking.

Malcolm Parker: He had a terrible, disfiguring cancer, and this was causing him great distress. Luckily, he was not in pain. He was mentally alert. But he was in a Catholic institution, which was a very good supportive palliative care institution. And one day, one of the priests came down to visit him, just to say hello – well, that's what he thought. But it really was to try and convince him not to stop eating and drinking, which was perfectly lawful, and it's encouraged as an alternative to assisted dying. He thought he might die in about three days, and of course it took three weeks. But it's an example of where a little bit of pressure can be brought to bear.

Andrew: What do you think was motivating the priest to urge your father to change his course?

Malcolm Parker: I think there's a strong feeling that we should support life at all costs, and nothing should interrupt that because it's not up to us to make these kinds of decisions.

[PENSIVE MUSIC]

Andrew: Nowhere is the Christian mission to restore hope and meaning to a dying person's life more powerfully expressed than through palliative care. Here, again, is Cabrini Hospital's Head of Palliative Care, Associate Professor Natasha Michael, giving an oration in 2018 to The Australian Catholic University, titled 'Widening the Doors of Hope.'

Natasha Michael: Our Christian – and indeed our palliative care – tradition embodies a moral tradition of fundamental convictions about what it means to die well. We seek to comfort those who are ill, whether or not they can be physically cured. We do so by being a sign of hope so that others may live and die in hope. In this we find the Christian vocation that makes our healthcare truly distinctive.

Andrew: More than half of Australia's palliative care is supplied by Catholic institutions such as Cabrini, reflecting the movement's religious roots, as Dr Roger Hunt, South Australia's pioneer in the field, explains.

Roger Hunt: The early hospices in the UK were funded by churches and charities named after saints, and the early leaders had strong religious beliefs, and those beliefs informed the

rhetoric around the end of life and the meanings that can be applied to it. That did lay out a pathway for what a good death should be, and the problem is that not everybody complies with that vision.

Andrew: Part of that vision is a belief that dying can be an important time for spiritual growth. As 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: While offering hope, comfort, and love to those who are dying is an admirable mission, not everybody values such help, however well-meant. Hobart Hospital's Professor Michael Ashby has written:

Michael Ashby: It is not the role of any healthcare team to suggest that its ministrations can give meaning, purpose, and dignity to a dying person's remaining life if that person feels that these are irretrievably lost. Palliative care is a model of care, not a moral crusade.

Andrew: I asked him what lay behind these words.

Michael Ashby: I would hold the view that these matters are deeply personal. People should be able to determine what is unacceptable for them, what they would not want to live with. It's not up to me to tell other people how they should die.

Andrew: Dr Roger Hunt shares this view, also acknowledging that palliative care can improve people's final days in ways beyond the medical.

Roger Hunt: Good things can happen. Perhaps restoring relationships, maybe estranged family members come into the scene. The love and care that can be provided in a hospice can brighten a lonely person's existence. I've heard some people say, 'These have been some of the best days of my life.' But bad things can happen in those last days as well.

Andrew: Bad things that can take away what makes a life meaningful.

Roger Hunt: There comes a point, I think, where most people will see that the remainder of their life is not worth living. The only future that's really there is more suffering. And of course, nobody but that person could make that declaration.

Andrew: In Dr Hunt's experience, it is the totality of this suffering that leads to requests for help to die.

Roger Hunt: That idea that, 'I have this identity, I've lived my life, this is who I am, but I can no longer do any of those things, and I never will be able to again. My meaning and my purpose in life has disappeared.' And if there is physical suffering layered on top of that, then this sort of thing does lead to the request for voluntary assisted dying. As good as palliative care gets, we'll never be able to resolve all of these issues for all people.

Molly Carlile: For me, it has to be about, 'Why are we doing this? Who is it for?'

Andrew: This is Molly Carlile AM, senior palliative care leader, whose career stretches back to the earliest days of the profession in Australia. Although raised and trained within the Catholic tradition, she, too, struggles with the projection of other people's values on those who are dying.

Molly Carlile: I don't think anyone's got a right to say to somebody else, 'You can't make a decision for yourself. You've got to listen to what I say because I know better than you about what you need.'

Andrew: Yet, The Vatican says that a plea for euthanasia is never to be understood as a genuine cry for death; it is to be understood as an anguished plea for love. So, you just rolled your eyes then. Is that something that you've heard or experienced before within Catholic palliative care?

Molly Carlile: I have, and I've got to say, soon as someone – I don't care who it is – thinks they know what everyone else's behaviour means, I just turn off because nobody knows that.

Andrew: Like Molly Carlile and Roger Hunt, Professor Ashby has been working in palliative care in Australia since its early days. He actually met and worked with the movement's founder, Cicely Saunders...

Michael Ashby: A towering pillar of modern medical and health history. Absolutely remarkable woman.

Andrew: ... yet sees problems with an over-emphasis of the values on which she founded palliative care.

Michael Ashby: There was a real need to sell this thing, to try and get visibility for services and, and yes, yeah, there was an ideology. We need to look at death and deal with it, and we have the means to do so. What that, I think, has engendered within the specialty around the world is what I would call a kind of kind of dangerous omnipotence. So, 'In palliative care, we've got the secrets of death and dying, if only you'd listen to us, it would all be alright.' And if you agree with assisted dying, for instance, then somehow, you're letting down the side.

Molly Carlile: The complex thing is that it is, for some, a matter of ethics and faith and morals, and I think that muddies the water.

Andrew: Like many in palliative care, Molly Carlile had been a vocal opponent of assisted dying. But as she thought more about the issue, she began to see her rejection of others' end-of-life choices as:

Molly Carlile: 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 Denton: Why do you think that is such a hard line for people to cross in the way that you've crossed it?

Molly Carlile: *[SIGHS]* I don't know the answer to that. I think there's a strong, very conservative group within the wider palliative care sector who have been leaders in the field, and some may not feel confident enough to say what they really think. Because I know of a lot of people who support VAD, but who would never ever say it out loud.

[SOLEMN MUSIC]

Andrew: In his 2008 submission to a senate end-of-life inquiry, Professor David Kissane wrote of the need to identify, and treat, demoralisation so that hope can be maintained even as death approaches.

'Patients with advanced cancer can be guided to focus on "being" rather than "doing," he wrote, "savouring the experiential moment of the present, so that purpose and meaning are preserved through inherent regard for the dignity of the person."

Undoubtedly, for some, such efforts to address the existential suffering which often accompanies dying can make their last days less painful.

But then I think of Phil Ferrarotto, who we met earlier in the series. Phil had Lynch Syndrome, a rare, incurable, genetic mutation that saw so many cancers cut out of his body he became something of a pin-up boy in oncology circles. Once it got into his bones and his spine, there was nothing more anyone could do. His daughter Katie recalls him lying there, with much of his jaw and neck removed, looking, she said, 'like a medical experiment.'

Katie Harley: This was complete agony. It was with every breath. To breathe hurt, to swallow hurt. He hated every second of it.

Andrew: I think of Shayne Higson's mum, Jan. We met her in episode 11, dying slowly, painfully in hospital of multiple brain tumours, victim to horrendous seizures. When she asked to be put into a coma, she was told she was depressed and in need of a psychiatrist. Here's her daughter:

Shayne Higson: She said things like, 'Why are they torturing me? Why are they so cruel? This is torture.'

Andrew: And I think of my father, Kit, who I watched die of congestive heart failure over three days. Kit, a fiercely intelligent, highly educated man who knew his own mind. Here he is, back in 1986, 11 years before he died, on Channel Nine's Today Show, being asked about euthanasia.

Liz Hayes: Kit joins us this morning. Good morning.

Kit Denton: Morning.

Liz Hayes: You obviously have a very personal belief about euthanasia. You believe in it?

Kit Denton: Mmm, yes, I'd like to practice it. Think about what it means: good death. It means not dying in a screaming welter of pain.

Andrew: I wonder how Kit, who did die in pain, would have reacted to being told that his thinking was not rational, that his was a mental health issue?

[PENSIVE MUSIC]

Andrew: In its statements down the years addressing euthanasia and assisted dying, The Vatican has been clear about the role of Christian doctors and nurses who care for the terminally ill, urging them to share in the evangelising work of The Church.

'If you are a Christian healer,' The Vatican says, to help someone die, means to 'help him to live intensely the final experience of his life.'

According to their beliefs, sickness and suffering, when 'borne in union with the suffering of Jesus', assume 'an extraordinary spiritual fruitfulness.'

Undoubtedly, there are those for whom this is both powerful and true. But for all?

I put to Dr Roger Hunt Professor Kissane's words about dying patients with advanced cancer 'savouring the experiential moment of the present.'

Roger Hunt: I can hear some of my patients' response with expletives to that sort of paternalism. I don't see it like you have to make sure everybody lives out their last days because of the chance that they might find an extra thread of meaning in their life. They have their own sense of what's happening, their own way of dealing with it with their own integrity, and many people in that situation are very rational. They don't have a psychiatric condition. It shouldn't all be looked at as pathology, as Kissane is trying to promote.

Andrew: Like meaning, faith is a deeply personal matter – one that Professor Ashby has seen work on many levels.

Michael Ashby: I've often been asked, 'Do you see people with a true religious faith going through this easier than those who don't?' And my answer is, 'Not really.' I've seen lots of people who are avowed atheists or agnostics who appear to have a remarkable capacity to deal with what the dying process brings for them. I've seen people of fundamentalist faiths having a very miserable time, as they believe that they are letting down their church communities praying so hard. In the dying process, I've seen the beauty of the rituals of Christianity, Judaism, Islam, Buddhism, so I think our spiritual and religious traditions are a rich part of our journey, for good and ill.

Andrew: What he struggles with are the hard-line politics of Church leaders when it comes to assisted dying.

Michael Ashby: I think the Catholic hierarchy are defending a position which is not defensible in lived life. I understand in theology the thread of life, I get that. But boy oh boy, this authoritarian streak and the tactical behaviour of The Church in the debate I think is very disappointing.

Andrew: In Australia, I have yet to hear a leader of The Catholic Church say, as Anglican Archbishop Desmond Tutu once said:

‘In refusing dying people the right to die with dignity, we fail to demonstrate the compassion that lies at the heart of Christian values.’

Instead, it seems, they insist their meaning be found in someone else’s suffering.

According to The Vatican’s 2020 missive on care for the terminally ill, anyone who chooses assisted dying is to be refused the sacraments, including confession and anointing of the sick. Unless the person recants on their choice, it instructs that priests should leave the room before they die, lest their presence be interpreted as approval.

Imagine: on your deathbed, a lifelong Catholic, and the priest turns and walks away.

[SOMBRE MUSIC]

Andrew: Over the last five years, I have observed the many different ways in which the Church hierarchy, and medical professionals sharing their worldview, have sought to represent those who request assistance to die, and the suffering from which they seek relief.

That they’ve never seen it.

Peter Abetz: ... I never once saw anyone die in agony.

Andrew: That good palliative care can make it disappear.

Stephen Parnis: ... the causes of suffering go away.

Andrew: That those who seek to end their lives are demoralised and acting irrationally.

David Kissane: ... that interferes with their decision-making capacity.

Andrew: That it’s really all just a cry for help.

Megan Best: ... euthanasia requests... they are usually a cry for help.

Andrew: That if meaning could be restored to their lives...

Natasha Michael: We know that people who lose a sense of meaning have these thoughts.

Andrew: ... if their loneliness were addressed...

Mark Coleridge: They want to end the pain of loneliness.

Andrew: ... if they weren't made to feel like a burden...

Stephen Parnis: ... people saying that they want to take their life is because they feel that they are a burden.

Andrew: ... if they were just shown the right kind of love...

Mark Coleridge: ... the great mystery of an infinite love.

Andrew: ... then they would not be tempted to weakness...

David Kissane: ... the 'giving up, given up' syndrome. Others have called it 'given-up-itis,' or mental defeat.

Andrew: ... and their suffering would be made bearable.

Mark Coleridge: ... allowing God to be God and life to be the gift and blessing that God wants it to be.

Andrew: But the brute reality is that some suffering at the end of life is neither bearable, nor treatable.

And there is another reality – surely, now, undeniable – that the first year of Victoria's law has shown us: the people who request assistance to die; who go through the long and difficult process of proving themselves eligible for that life-ending medication; and have the courage to drink it because there really are some things worse than death; these are not people acting out of loneliness, or depression, or fear of being a burden, or loss of meaning – though all of these things may be part of their dying.

These are not demoralised, irrational, broken people crying out for spiritual help.

No, they are strong; facing their reality; choosing to control their dying before it takes them apart, piece by piece. And the help they want is a law which delivers them that choice.

A law for which they are deeply grateful.

[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 final episode of Better Off Dead: opponents of Victoria's assisted dying law predicted it would be too easy to access, leading to wrongful deaths, but the opposite has turned out to be true.

Kristin Cornell: He was desperately short of breath, and his ribcage, trying to breathe, and skin on it, and twitching muscles, and *[VOICE BREAKING]* this isn't what he wanted.

Andrew: What are the unintended consequences of a law designed, for political reasons, to be 'the safest of its kind in the world'?

Betty King: We've never had a complaint about it being too quick. Only ever had complaints about it taking too long.

Andrew: What has it meant for doctors?

Andrea Bendrups: You can talk about palliative care, but you're not allowed to tell them about VAD, which is a bit mad to me.

Andrew: And what has it meant for those who are dying and the people who love them?

Kristin Cornell: All the worry that, unless we get 50 people to double check that you're of sound mind, that we're all going to be wanting to do voluntary assisted dying – are they out of their minds?

[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]