

Episode 11—Whose life is it anyway?

[SUICIDE WARNING]

[PRAYER BELL CHIMES]

[Ethereal female voice]: There is no death. There is only me, me, me who's dying.

Richard Chye: I'm not going to say I'm going to control everybody's physical pain – no, I'm not going to be able to do that, because there will always be some patients who will have pain that is not controlled. And I accept that, but I also make sure that I tell patients, “This is the best I have done, this is as much as I can minimise your patient's pain, but I am going to help you live with that pain”.

Andrew Denton: Professor Richard Chye is the director of the Sacred Heart Palliative Care unit at St Vincent's hospital in Sydney. He's invited me to spend a week with his team to see what they do and, also, to discuss the subject of assisted dying.

Two things have been obvious while I've been here: the compassion and care from the staff, as they help people to die in, often very complex circumstances. And just as apparent: a deep resistance to the thought of assisted dying. Exactly how deep, I didn't realise until I sat down to speak with Richard.

[OPENING TITLES]

Andrew Denton: Richard Chye is a gifted physician and teacher. He is also a hugely influential figure in palliative care in Australia. Apart from being a member of various state and national committees he's a board member of Palliative Care Australia, the peak national organisation.

So what does the expression “death with dignity” mean to him?

Richard Chye: Death with dignity means that patients have died comfortably, from a physical and existential point of view, that they are not thrashing around as they die, that love is still expressed by all between patient and family, and that patients are able to slip away in their sleep when it is time and therefore it is not for me to say when that is because it is the patient and his or her maker that decides when that will happen.

Andrew Denton: What symptoms are most difficult for you to control?

Richard Chye: The most difficult symptom is existential

Andrew Denton: That's interesting. What is that? How do you define it?

Richard Chye: It's distress, a patient's distress about their condition, their illness, what it is doing to them. That I think is the most difficult symptom to try and get over. Because it is not a physical symptom like pain or nausea, vomiting; it is an acceptance, it is a mental anguish.

Andrew Denton: And that is entirely understandable distress.

Richard Chye: Yes. And therefore what I try to do is to try and say to these patients, “These are the medications that we can use to help your pain, to prevent nausea, and these are the people who can help you to the bathroom and make sure that things are still very dignified for you and that we are here to help you understand what the illness is doing for you”.

Andrew Denton: Palliative Care Australia acknowledges that even with optimal care not all pain and suffering can be relieved. What are the kind of cases where you see a situation like that?

Richard Chye: I think there will always be patients who will have very difficult pain, Thankfully, they're actually very unusual, very rare, very commonly we'll need to resort to more than medication, so you may actually have to do a nerve block, we may have to do an epidural into the spinal cord to numb everything. So very, very few patients die in physical pain, and I think that is important to know.

Andrew Denton: Of course all pain is mental. Whether it's physical or existential it is your brain that processes it. And, if it's your pain, then the question you are most likely asking yourself is: “can it be stopped?” According to Richard Chye, not always...

Richard Chye: I'm not going to say I'm going to control everybody's physical pain – no, I'm not going to be able to do that, because there will always be some patients who will have pain that is not controlled. And I accept that, but I also make sure that I tell patients, “This is the best I have done, this is as much as I can minimise your patient's pain, but I am going to help you live with that pain”.

Andrew Denton: Although palliative care is a place for the dying, Richard's focus is very much on how people can get the most out of the end of their life. That means walking a delicate line between doing everything to make the patient comfortable, but not prolonging their life unnecessarily. It is the credo of palliative care: “We will neither hasten nor prolong death”. I ask Richard what this means in practice.

Richard Chye: In terms of prolonging death, it is to make sure that we give the right treatment to the right patient at the right time, I think that if the chance of surviving the disease is very poor, then giving treatment to prolong that by a couple of weeks is prolonging death.

Andrew Denton: So what is the difference between not prolonging death but not hastening it?

Richard Chye: Not prolonging death is allowing the disease to develop naturally, with a view of not prolonging suffering, with a view that patients are comfortable for the time that they have left ... and yes, I recognise it is not an easy thing to differentiate to say why is it different from hastening somebody's death by giving them an injection, a lethal injection. And I think that's not an easy concept. But then again, it is normal to have those feelings as well, it is normal for me to say, “I wish I could give you something that will kill you earlier so that you don't have to go through that suffering”. That is a normal emotion to have. And again, I think if you don't have this emotion, then I think I will be worried about myself and how I look after my patients.

Andrew Denton: Have you been involved in cases where you have unintentionally hastened a patient's death?

Richard Chye: I don't think so. I can't think of any instance where I have, when you say, unintentionally hastened a patient's death.

Pain medication is given every four hours, so there will be a small percentage who will die at the end of a needle, and people will say, oh, the morphine has caused it, when in fact there was always going to be a chance that some patients will die at the end of a needle. And some people then foresee, "Oh well you have given a needle, it has caused the death; you have euthanased them", when in fact they were going to die anyway.

Andrew Denton: And as you say, your primary intent is to manage pain. If, however, the medication isn't capable of managing the pain, is there a limit to the amount of medication you will give?

Richard Chye: Yes. More doesn't mean better – only in the Chinese culture it is. [Laughing] But more opioids, just increasing the dose, doesn't mean the pain will get better. I have to actually think of other ways of controlling pain, like other nerve medications, neuropathic agents – methadone, for example. I have to think about whether a nerve block or an epidural, that we talked about, has a role, because more of the same I think is not likely to work.

Andrew Denton: And if that combination of things doesn't work – I know we are talking about a small percentage but that percentage exists – what then?

Richard Chye: I walk with the patient. I say to them, "Yes, we have done our best to control your pain, yes, the pain is still there, but I will help you live with that pain". The patients who have committed suicide on my watch were not in pain, not in physical pain. The patients who committed suicide on my watch feared that they will have pain.

Andrew Denton: That is a jolting thought – that some people are so frightened by the prospect of dying they would rather kill themselves. All the more disturbing in a place where they know they have come to die. And what of those who actually ask for help as they near the end?

Andrew Denton: Palliative Care Australia acknowledges that there are patients who make rational and persistent requests for a hastened death. In what situations would that occur?

Richard Chye: I think in patients who don't want to live the way they are, who have not accepted that their lives have changed.

Andrew Denton: And when a competent adult makes a rational and persistent and sincere request for a hastened death, how do you respond?

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

Andrew Denton: Bang. So there it is. Clear and unblinking. No matter the authenticity or desperation of a dying patient's request, Richard's medical response will ultimately be decided according to his morals. And this is not just anybody. This is the man in charge of palliative care.

It makes me wonder. Whose life is it anyway?

Andrew Denton: Richard Chye is a powerful voice in the Australian palliative care community. But he is not the only one.

Ian Maddocks: I'm Ian Maddocks and I'm retired. I was a palliative care physician for the last 28 years and I'm now losing sight and hearing and unable to be useful to people. So here I am.

Andrew Denton: Professor Ian Maddocks is known as the father of palliative care in Australia. He was first Chair of Palliative Care at Flinders University, first President of the Australian Association for Hospice and Palliative Care and first President of the Australian and New Zealand Society for Palliative Medicine. Now retired, he sees the question of assisted dying from a very different perspective to Richard.

Ian Maddocks: I think that you try to do the loving thing in whatever situation you land, and while the Catholic debate will talk about love as being the most important and God's love can keep you, love has got many ways of operating I think and I believe that assisting someone to die can be a loving act.

Andrew Denton: Can you explain to me in practice what the central tenet of neither hastening nor prolonging death means?

Ian Maddocks: So what does it mean to those people who practice palliative care? It's a defence against any accusation that they are using drugs that will shorten life. It's a defence also against thinking that they've got too strong an emphasis on continuing life, because they don't want to have that either. On either count I think it's a bit of a defensive sort of stance.

Andrew Denton: Is there some suffering that can, in truth, only be relieved by death?
IM: It's tricky but usually you can do something for physical suffering. It's the social suffering of the family and the patient together, the grief – these are the things that are telling and...

Andrew Denton: Is this what's referred to as existential pain?

Ian Maddocks: I suppose so. I don't use that term much myself. It's personal discomfort that you really have to try and tune in to and understand, and again, it's why you need to walk beside people and you need to walk with the family as well. Because then you get a better picture I think of the whole thing that we're facing, and the strategies that you try to design need to take into account all those sorts of things.

Andrew Denton: From the patient's point of view though there might not always be something you can do. It may be to a point where they don't want something done.

Ian Maddocks: Well they don't want to, that's right, and they quite rightly, and you've got to respect that. "Look, I can do this and I can do that". "Oh stuff that, why don't you just finish this?" And that's where the drugs sometimes do too much and they make people too asleep. They're too comfortable in a sense. And some people will tell you, "Look, I don't mind a bit of pain but let me just be awake".

Andrew Denton: Have there been any occasions where being entirely honest with yourself you know that your actions helped hasten somebody's death?

Ian Maddocks: Yes, yes, yes, and very rarely. They've usually been situations when I said if you take this and this and this, or I've given an extra dose of medication because the whole thing was hopeless and the family are saying, "Can't you do something?" But it's very uncommon in my experience.

Andrew Denton: And the fact it's uncommon reflect absolutely what happens overseas where these things are legal. It's a very small number of people.

Ian Maddocks: It's not going to be huge flood of people requesting and wanting, I think. People want to live, on the whole, and sometimes they want to live when you say, "For God's sake, why do you want to live?" But they do.

Andrew Denton: Is this something that you also know of your colleagues, that they have been in similar situations?

Ian Maddocks: It happens. It must be happening because if you're doing sensible things for particular situations, there will occasionally rarely be things where you feel that this is the right thing to do, I think, and unless you've got an absolutist point of view, which some people have, then you will probably try to do something sensible.

Andrew Denton: Ian is right. Even without a law, doctors in Australia have been assisting people to die for years. Not only did I get this anecdotally from many doctors I spoke to, surveys confirm it.

In 1997, national research into the decisions doctors make while caring for dying patients found that euthanasia, including physician-assisted death, accounted for nearly 2% of all Australian deaths.

In 2001 a national survey of general surgeons revealed that more than 20% had hastened death by giving more medication than was necessary – without the consent of the patient.

And, in 2007, a survey of Victorian doctors showed that, of those who had experienced requests from patients to hasten death, 35% had administered drugs with the intention of doing so.

So Ian Maddocks is just one of, perhaps, thousands, of doctors in Australia who have practiced assisted dying. Only we don't really know how many. Or whether they're doing it well, or for the right reasons, or with the consent of patients – as they do overseas – because the absence of a law here means we have no guidelines, no reporting mechanisms, and no system of review. Everything has to stay in the dark.

All we have is doctors doing what they believe is best, depending on their moral view of the universe. Which brings us back to Richard Chye. Even if his morals allowed, Richard doesn't believe a safe law for assisted dying can ever be created.

Richard Chye: What I fear most is whilst legislation safeguards whatever is put in place to help an individual right to be assisted to die, what my fear is that it will lead to – because of bad apples – to people who are put to death or assisted to die without their consent for somebody else's gain. And I think that whatever safeguards that you have in place, or that the government has in place, is going to not prevent those things from happening. I see that commonly, that it can be misused for personal gain or somebody else's gain.

Andrew Denton: When you say you see it commonly, what do you mean – here?

Richard Chye: In Australia. Yes.

Andrew Denton: Can you give an example?

Richard Chye: I remember a case where it actually went to court, about someone in the northern beaches who – I think that two ladies – and I can't remember them – admitted that they actually "euthanased", in inverted commas, their loved one for personal gain.

Andrew Denton: And I'm sure the law dealt with them.

Richard Chye: The law dealt with them, but unfortunately that patient died.

Andrew Denton: Absolutely. But you see that is happening without any scrutiny.

Richard Chye: What I fear, however, is its implications.

Andrew Denton: Meaning?

Richard Chye: Meaning if I do give something, a lethal injection, to end somebody else's life, what are the implications for the next patient? How am I going to look after the next patient, who doesn't deserve, doesn't want it?

Andrew Denton: That would be a fair question, but under a law, it would be very, very clear, because only the patient could request it.

Richard Chye: Yes and no.

Andrew Denton: Well, yes – that's how it works.

Richard Chye: Patients can request it, yes. I think the difficulty is what do we accept as a patient want?

Richard Chye: One in 20, 5% of my patients, will express to me that they have had enough, that they wish they died, had a good innings, don't want to live longer than they should, but does that mean they all want to die there and then? And I think that is a thing that can be misconstrued very, very quickly.

Andrew Denton: Ian Maddocks sees a law as, not only desirable, but clearly workable.

Ian Maddocks: I have said on a number of occasions that I would like to have an assurance that if I did something sensible with loving care and without haste and transparently, that I would not be guilty of a criminal offence. But I think it would be possible to write not a law that tries to define the circumstances in which you may kill somebody but says that if doctors have done it without haste and for clearly reported and explained suffering, then the doctor is also given the excuse, but he has to report it, he has to have perhaps some oversight.

You've got to be transparent about it, you've got to write it all down, you've got to have – after you've done it, you should report it to the coroner and say, “This is what I've done and here are my records to go through”.

Andrew Denton: The business of dying is as complex and individual as the people who come to palliative care. No-one knows this better than Richard Chye, who, despite his opposition to assisted dying, is nonetheless a believer in patient autonomy.

Richard Chye: We doctors don't give control to our patients, because we want to treat, and I think that is something that we haven't yet taught our doctors yet – you have to listen to your patients, you have to ask your patients what they want and what they don't want, especially the parts about what they don't want.

Andrew Denton: In the name of autonomy, Richard confirms that there is one way – in fact it is Palliative Care Australia policy – where it is OK to assist a patient should they wish to bring an end to their life more quickly.

Richard Chye: It is part of the principle of autonomy that patients have the right to refuse treatment even though that treatment may prolong their life.

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

Richard Chye: Yes they do.

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

Richard Chye: That's a very good question, and I have seen patients go in two or three days and I had a patient who went after three weeks, so it varies, and it is according to how much – what I would call, in inverted commas, “reserve”, how much reserve they actually have left in the body that can keep them going, so how much food have they consumed or were given just prior to stopping.

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

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

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

Richard Chye: Yes.

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

Richard Chye: I think Palliative Care Australia, and I guess also from my point of view, we are very keen to understand what patients want. So if a patient wants to stop treatment and die as a result of their illness, then that is something we would be very happy to accept, especially when the treatment, was likely to cause more burden than benefit, then yes, by providing good palliative care, by providing good psychosocial and symptom management, then that is the right thing to do for that patient. I think for a patient to actively say, "Put me to death, kill me now!" I think that is a fundamentally different thing, because whilst my intent in palliative care is to keep patients comfortable as they die, my intent is not, definitely not, to kill patients.

Andrew Denton: Yeah, no, I certainly understand that. From the patient's point of view, though, I would imagine there is zero difference – you know, "I want to die, I don't have the option of dying quickly because it is not available here, so I will die as quickly as I can" – which unfortunately might be two or three weeks.

Richard Chye: Thankfully that is very rare, that two or three weeks, but yes, I think it is uncomfortable for these patients to think that they are taking longer to die, and it is also uncomfortable for families to say they are taking too long to die.

Those patients who are waiting a long time to die, those families who are waiting for their loved one to die who are taking a longer time, what it means for us is, "Yes, I acknowledge, we acknowledge that it is taking longer, but we are still going to provide you with the best care that we can".

Andrew Denton: And I don't doubt that, but to me it still sounds very tough. That patient who is beyond any medical help, who has determined that they wish to die but whose only choice is to have a longer, slower dying – two, three days – two, three weeks – to whose benefit are they being kept alive?

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

Of all the things that I learnt during the making of this podcast, I found this to be the most shocking: That it is ethically – officially – acceptable in Australia for a patient to choose to die slowly and painfully by means of dehydration and starvation. But it is ethically unacceptable for that same patient to choose a death that is painless and quick.

Since that conversation I received a letter, unprompted, from Jason in Queensland. He wrote of his dying wife, Melanie:

"At the moment, she's lying next to me in her hospital bed slowly dying from pancreatic cancer. It has been 10 days without any food or drink and she has now deteriorated to just a

shell of the woman she used to be. She's not in pain ... but it's hardly dignified – she would not have wanted to go out like this.”

Jason wrote to me again a week later. He wanted to emphasise the heroic work of the palliative care team in caring for his wife. But he added this:

“The last five days or so were particularly bad. There were very few signs that Melanie was conscious at all, and letting her lie there gasping for air just seemed cruel.”

Melanie was just 38.

Andrew Denton: I was talking with Dr Redelman about this the other day, and he referred to euthanasia or assisted dying as murder. Is that how you see it?

Richard Chye: If there's the intent of actually killing a patient, then yes, it is murder, because murder is the intention to kill.

Andrew Denton: See, this is where I am really interested, because you and he are both really intelligent, compassionate men. Do you not see a distinction between an unrequested act of violent aggression and a sincerely requested act of medical compassion?

Richard Chye: But the intention is still there. The intention doesn't change.

Andrew Denton: No, the intention is the patient's intention. It is not an intention from someone else to murder someone; it is a request for help from a patient to help me die. Do you not see a significant difference there?

Richard Chye: No, I think there is a difference, because it is what I do to hasten a patient's death. It is my intention. It is not a patient's intention I am talking about.

Andrew Denton: OK, that is kind of at the heart of it, because you were saying before doctors need to be better at listening to their patients, so isn't this about the patient's intention?

Richard Chye: It is the patient's intention to want to die, yes. But for me to assist in that is also my intention, my personal intention as a doctor, to actually enact that.

Andrew Denton: On one level, I have no argument with Richard. His morality is his and he is entitled to hold to it. But should his be the only view allowed? Death is much more than a medical experience. As one poet described it “Death is the last intimate thing we do”. Shouldn't the patient's wishes about this deeply personal act also be considered?

In Oregon, the Netherlands and Belgium the law allows doctors and nurses with moral objections to assisted dying to refuse to participate. There is no need to explain. No question or censure. They simply opt out.

Those who see assisted dying as consistent with their medical duties act, also, according to their conscience.

In Belgium, I met a Jesuit priest who was also a palliative care doctor. He had ethical objections to assisted dying and so he would not perform it. But, if a patient of his chose the option within palliative care, then he would do everything to prepare them, physically and spiritually, up until their final moments before putting them into the care of another doctor who would legally help them to die.

Everybody's conscience remained clear. But it was the patient's wishes that were considered to be the most important thing.

Every year Wollongong University's Health Services Unit collects data from the 106 Palliative Care units across Australia. The most recent showed that one fifth of patients in the last 24 hours of life endured moderate to severe pain despite the best efforts of palliative care; 30% of families watching their loved ones die also experienced moderate to severe pain. Shayne Higson knows this pain all too well. Her mother, Jan, contracted an aggressive form of brain cancer. At first she was nursed at home by the family, with help from palliative care teams.

Shayne Higson: Well Mum ended up – her quality of life had deteriorated to a point where she couldn't read, she couldn't write, she could hardly speak, she was bedridden, she'd lost all feeling down one side and she would try to describe what it felt like. She felt that her body was already half dead.

Andrew Denton: In her last months Jan began to suffer terrible seizures.

Shayne Higson: And she was seizing for – I don't know how long – well over an hour, maybe couple of hours. She said it was like a giant thrashing around in her body. The brain, as you know, it creates all sensations so things were happening in her.

She kept shaking, and of course in the back of my mind was that was what she feared the most – was having another seizure. She said “Whatever you do, do not let me have another seizure”. And so I knew that through the whole six months that was what she feared the most, because of how dreadful it felt to her. And she kept shaking. When she didn't stop shaking, we said, “Can you give her more? It's not working”. He said, “I can only give her this amount and every 15 minutes. I'm not authorised to give her any more. If I give her more, it might end it”.

Andrew Denton: Like many people, Jan had always believed that when the time came and the pain of her cancer became too much, doctors would “do something” to prevent her suffering.

Shayne Higson: She was very clear what she wanted and she'd said it right at the beginning as well. But they're not allowed to. That's the thing. once she went into hospital, that's when I really realised that it's just not allowed. It's not allowed. The terminal sedation which is the best option that we have now, does not guarantee a peaceful end.

Andrew Denton: When you spoke to the medical staff –when you spoke to them, you said to them clearly, “My mum wants to be knocked out”. Do you recall clearly what they said to you in response or was it a vague sort of obfuscation?

Shayne Higson: No they actually said, “I think your Mum might have depression”.

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

Shayne Higson: Yes.

Andrew Denton: She had a major brain tumour.

Shayne Higson: Multiple.

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

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

Andrew Denton: With days to live, Jan was moved into the palliative care unit at a private hospital. She was in such pain that her family begged she be given something to knock her out.

Can you tell me about Jan's last days because there was still a lot of pain ahead, wasn't there?

Shayne Higson: Yes, it was sort of a bit of a really difficult time because she was having trouble swallowing and all her medication was in tablet form, and it was such a battle. She stopped eating.

Andrew Denton: As the end approached Jan spiralled into greater pain.

Shayne Higson: They did say that at the end if they go off the medication it ends it quicker but it's not pleasant. Just seeing Mum so – the one side of her that that was okay, on the second night she was thrashing her head from side to side, and the leg was going up and down, up and down, up and down.

So it's like seeing someone thrashing around but only with half their body. And again you know we called in the staff and tried to get medication that would ease that suffering and the distress and agitation. And it took, again, ages before they were able, because they're not allowed to give – they're so frightened of giving doses that may end it.

Andrew Denton: So the best that they were prepared to throw at it clearly offered no genuine relief?

Shayne Higson: No, no. I thought that terminal sedation – not that I knew that that's what it was called, but the way that the GP had described it – and I've heard it described now –

where they put you into a sort of an induced coma, I was picturing, where there would be no suffering, but that's not right.

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

Shayne Higson: Five. Five days. She went in on Thursday and she died on Tuesday morning.

Andrew Denton: So five days of largely unrelieved pain and distress for her of course – also for you – and at no point was anyone prepared to go, “We can do more”.

Shayne Higson: No. No, not a nurse or doctor anything.

Andrew Denton: The strong sense I get as I'm listening to you is that you must have all felt – and above all your mum – completely powerless and helpless in this situation.

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

Andrew Denton: Did your mum get any peace before she died?

Shayne Higson: I wouldn't say so. It wasn't peaceful and the look on her face at the end, yeah, showed it was not a peaceful end. And if that's the best that they can offer sort of thing, it's not – we can do better than that.

Andrew Denton: What happened to her mother spurred Shayne to stand for the Senate as a candidate for the Voluntary Euthanasia Party.

Shayne Higson: I'm happy to speak to any of the opponents and say, “Tell me what happened to my mum is right, is humane, is compassionate – because it wasn't, and they can't deny what happened to Mum. I mean I've recorded it and it happened. The doctors can't deny what happened.

They can't really say that it wasn't good palliative care because actually Mum had the best palliative care.

Andrew Denton: What Shayne's mum went through was far removed from anyone's description of death with dignity. The scars it left behind, for Shayne, may never heal.

Shayne Higson: That last few weeks, I felt like I let her down and I didn't get the love and the goodbye that I would have liked, that I think everybody deserves when you love someone like a parent and you've taken care of them. But she would have felt let down. She sort of said things like, “Why are they torturing me? Why are they so – meaning the doctors – why are they so cruel? This is torture,” and it was. It was torture to force her to endure that end.

Andrew Denton: Shayne's story, and others I had heard like it, were very much in my head when I sat down for my last conversation with Richard Chye.

Andrew Denton: I have spoken with people who are still alive who have been through palliative care in Australia, for whom the pain relief hasn't really touched the sides. I have spoken with families who have seen their family members die in palliative care units in Australia begging for more medication and being told that there wasn't more or there wasn't more scheduled right now. Who could be more vulnerable than these people and why shouldn't they be protected?

Richard Chye: They are vulnerable patients, they are vulnerable people, and yes, if they are not getting the adequate symptom management, then it is a health system issue that we need to try and solve. So if someone's...

Andrew Denton: But you know why it is happening – we have discussed it – because there is a limit to how much in some cases pain relief you will give. You said so yourself the other day. And that limit effectively is: “I want to die, I need to die; I can't stand this anymore”.

Richard Chye: Part of the provision of palliative care is understanding, yes, the reasons for wanting to die. If pain is a very difficult symptom and it has led to a patient saying “I want to die,” then it invokes in me the need to do better, to try and improve that pain, and if I cannot improve that pain, then I try and help that patient live with that pain.

Andrew Denton: That's very tough if you are that patient, Richard!

Richard Chye: It is very tough, but I am not going to leave that patient. I am not going to leave the patient in pain...

Andrew Denton: But effectively you are. I am not saying you personally but effectively that is what you are doing. For those patients that can't be helped, that is effectively what you are doing.

Richard Chye: No, I don't agree with that. I think that I am not leaving that patient in pain. I...

Andrew Denton: Who are these people screaming for help that I have spoken to?

Richard Chye: That is a systems issue that I think we need to examine why patients are, as you said, asking for pain relief and being told it is not due yet.

Andrew Denton: It is your system though, Richard. And again, I am not saying you,

Richard Chye: I am saying it is palliative care, it is end of life care; it is your system. We are not perfect.

Andrew Denton: Of course not.

Richard Chye: We are not perfect in the palliative care system.

Andrew Denton: And you can't be. And no-one suggests that you can or should be because there are some things which can't be managed, which are beyond all your efforts and skills.

Richard Chye: But I think we need to look at – I think if someone is saying that I am in pain, we need to be able to look not only at the treatment but look at the system as well. Why is that patient not able to get pain relief? Is it because we have staff, not only in the palliative care arena but also in the hospital, arena, in terms of are they adequately trained? Do they have the resources to manage them? And I am saying at the moment no, I don't think we have all the resources that palliative care in Australia requires to be able to provide the best care that we can at this point in time, and that includes educating the rest of the non-palliative care health system about how to look after our dying.

Andrew Denton: And they are all good questions, and they should be asked and asked consistently; however, Palliative Care Australia says that even with optimal care not all pain and suffering can be relieved, and so for those few people, that small number of people that you can't help, you offer nothing. It is not a systemic failure; it is a deliberate decision. Let me ask you this – is it true that there is some suffering that can only be relieved by death?

Richard Chye: In medicine we never say never.

Andrew Denton: But in reality?

Richard Chye: I don't know.

Andrew Denton: Richard – this is the only time where I thought you were being disingenuous. I think you do know.

Richard Chye: I would feel that there will be times, and I think it is normal me to feel if I haven't controlled your pain or I haven't controlled your depression or your mood, yes, you are probably better off dying earlier than now. But that is not going to stop me from trying. It means that I acknowledge that the problem is difficult. It means I acknowledge to myself, to my team, to my patient that it is difficult, acknowledge that it is not easy to look after a particular symptom, acknowledge that I am going to be trying my best to help that patient, acknowledge that I am going to be with my patient to try look after that patient and try to minimise that suffering as much as I can.

Yes, in my heart I would think that this patient may be better off dying earlier, but that is a normal reaction, normal emotion for me to have, and I think that if I didn't have that emotion, I have to worry about myself, but it doesn't absolve me from abandoning my patient and trying.

Andrew Denton: Which is admirable, but with respect, what I hear there is about you but not about the patient.

Richard Chye: No, I also acknowledge with the patient that it is hard, acknowledge that the patient is going through a very difficult period, going through a lot of suffering, yes, acknowledge that. And that is part of that acknowledgement with the patient who understands that they are suffering. Yes, they will say this suffering is very hard for them and they would prefer to die, and I would say to them, “Yes, I acknowledge that you are feeling that way but I will continue to try and make you feel better so you don't have to feel that way”. So I don't see – it is not for me to say or not my practice or not my ethics or not my morals to say, “Because I can't look after you, you are better off dead, and I will pursue that end”. No, that is not me, and that is not palliative care.

Andrew Denton: And nor should it be. And as you know, under these proposed laws, it would never be you saying that; it would be the patient requesting it. I'll finish with Palliative Care Australia's statement that it accepts quality care at the end of life as a basic human right. Does that human right stop with somebody requesting to end their life by their own timing?

Richard Chye: I think quality care is providing the best care that we can, so that the patient is provided with good end of life care. I don't see providing euthanasia as part of the quality care, and I don't think Palliative Care Australia sees euthanasia as quality care.

Andrew Denton: There are others, perhaps many, working in palliative care in Australia, who share Ian Maddocks' view that...

Ian Maddocks: Euthanasia should be done the way we do palliative care and palliative care physicians should be ready to be part of it if they are allowed to and they feel able to. They should do it with love.

Andrew Denton: Make no mistake. To assist someone to die who is otherwise beyond medical help and who asks for that assistance is not an act of murder. They are already dying. What they seek is a compassionate choice about how it happens. Far from murder, it is an act of love.

Palliative Care Australia's official line, whenever the subject of assisted dying comes up, is to deflect it by arguing that the way to provide better care for their patients is through giving palliative care greater funding and more resources.

While no-one would argue that this is a bad idea – palliative care provides an important and admirable service – it deliberately skips over those patients who they cannot help, either by law, by the limits of medicine, or by the boundaries of their own morality.

It makes invisible Spencer Ratcliffe's partner, Deb, clawing the walls in pain and being told she has to wait for her next medication. It makes invisible Shayne Higson's mum Jan, thrashing in agony for 5 nights with a brain tumour because she was told "We can do no more". It makes invisible 38-year-old Melanie who took 15 days without food and water to die, the last 5 of which her husband Jason described as "cruel". It makes invisible those patients who have committed lonely suicide within palliative care rather than endure the slow grind of death. It makes invisible those 20% of their patients who – according to their own statistics – endured moderate to severe pain in the last 24 hours of their life despite the best efforts of palliative care. And it makes invisible those families who've had to stand by, helplessly, and watch as their loved ones die slowly and in pain.

My question is: "Why?"

Everyone I spoke to in palliative care acknowledges they exist – the "bad deaths" who they "wish they could have done more" for. Why aren't these patients the ones Palliative Care Australia are doing everything to help?

Why do they continue to reject any thought of assisted dying even though they must know that it would provide the relief they can't?

How can they already accept, in principle, that a dying patient has a right to hasten their own death, but reject that they have a right to choose how?

How can they claim to support patient autonomy yet, at the same time, allow the personal morality of their doctors to determine the choices of their patients?

And why do they continue to push the line that legalised assisted dying would detract from palliative care when overseas experience has shown that, in those countries where such laws exist, palliative care services have improved as a direct result?

If palliative care is truly – as Palliative Care Australia claims – about quality care at the end of life, then as long as patients are dying like Deb and Jan and Melanie, it is fair to question that claim.

In the 1980s, the nuns of Sacred Heart set aside their morality and threw open their doors to Sydney's HIV-ravaged gay community. It was a powerful demonstration of the love and compassion that lies at the heart of palliative care.

Assisted dying is love and compassion extended to those who are most desperately in need. I hope that, on this, Palliative Care Australia will look again, with clear eyes and honest hearts.

[SONG 'FORTY-EIGHT ANGELS' BY PAUL KELLY]

Andrew Denton: If you'd like to know more head to the episode page at wheelercentre.com/betteroffdead.

In our next episode we travel on the long journey with Ray Godbold, a palliative care nurse who is dying of cancer – but who doesn't want to die in palliative care.

That's because Ray knows what some doctors prefer not to admit: That, even in palliative care, not everything can be taken care of, that a patient's choices about how they die are very limited, and that, sometimes, their dying involves a wildness no-one can predict.

What Ray can't know is that his own death will turn out to be everything he was hoping that he and his family would be spared.

[CLOSING CREDITS]