

Episode 10 – Neither hasten nor prolong death: palliative care in Australia, part 1

[SUICIDE WARNING]

[PRAYER BELL CHIMES]

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

Nancy: People deal with it with anger, some people deal with it with just acceptance and some are in the middle. Some are angry but somehow they are resigned to the fact that they are going to die. And some people just want to get it over and done with.

Andrew Denton: That's Nancy, an Australian palliative care nurse. Speaking to doctors in Belgium, The Netherlands, and Oregon, I'd learnt that, in their countries, palliative care and assisted dying are seen as things that go together – assisting a patient to die, the ultimate offer of help for those beyond even the skills of dedicated palliative nurses and doctors. Back home in Australia, the law forbids assisted dying. Without a law to protect or guide them, I wanted to find out how palliative care here deals with those same kinds of patients?

[OPENING TITLES]

Andrew Denton: My name is Andrew Denton, and you're listening to *Better Off Dead*. I should warn you – the next two episodes may make you consider your own last days far more deeply than you ever have before.

When I asked Professor Richard Chye, the director of Sacred Heart Palliative Care Unit at St Vincent's Hospital in Sydney, if I could spend a week with full access to learn what it is they do, I was upfront with him. I told him I believed there should be a law for assisted dying in Australia – not a subject often raised within their walls, and that it would be one of many things I'd like to discuss with him and his team. To my surprise – and to his credit – he agreed. I started with nurse Therese Compton.

Therese Compton: I have worked at Sacred Heart for coming on – this is the beginning of my 11th year. And I've been a nurse since I was 17. I've always had an interest in – I really like looking after people who need care.

Andrew Denton: I walked past one of the wards today and I just noticed a woman stroking somebody's hair.

Therese Compton: Yes.

Andrew Denton: And that was a lovely thing to watch. It felt like a universal thing to see.

Therese Compton: Very much so, yes. I like people's hair to be done. I like people in pyjamas, like, their own clothes rather than a gown. And if they haven't got one, well we find something. I like the person to remain the person inasmuch as they can.

Andrew Denton: I want both my hairs done when it comes time.

Therese Compton: [Laughing] We'll see to that, Andrew.

Andrew Denton: People come to palliative care for many reasons. It might be cancer. It might be an autoimmune disease. It might be renal failure. It might take days. It might take weeks. Patients might even leave and then return. But they only come here because their days are numbered.

That's what makes palliative care different to any other branch of medicine. The aim is not to cure you but to make you as comfortable as possible as you head into death.

Andrew Denton: Can you give me some idea of the human parade that comes through here – the different lives that you see?

Therese Compton: You see everything from High Court judges to homeless people who have lived in the park for 20 years.

Andrew Denton: I suppose what you also see here is the truth of these people.

Therese Compton: Absolutely. Because you only come here if you need care. You've got to a point where you need your symptoms well managed, and you need some proper care. You need to be reviewed. You need to be managed, and things need to be put in place whereby the end of your life can be quality.

Andrew Denton: It's hardly surprising that, when people first arrive here, one of their strongest emotions is fear.

Therese Compton: People are afraid for a number of reasons. A lot of them it's their symptoms. They've got pain. They're feeling nauseated. They're exhausted. They're not managing their activities of daily living, so they're anxious about losing their independence. But they are anxious about – you know, the bigger questions of life and “What have I done with my life?” And “Has it all come to this?”

You can pretend for a little while, but reality hits. So everyone has to face that big question, you know – this is it.

Andrew Denton: By day, the palliative care wards are surprisingly full of life: beepers going off, constant chatter, phones ringing, trolleys and staff bustling. But, like the sea at night, in the small hours of the morning it all feels darkly different.

What time is it? It's 1.30 in the morning on a Saturday morning. It seems pretty quiet in here. Is it always this quiet?

Fran: No, not always. That depends on how many difficult patients we have.

Andrew Denton: I'm on the night shift with Fran, a registered nurse and 24-year veteran of Sacred Heart.

Andrew Denton: What is a difficult patient?

Fran: Someone who is climbing out of bed, who is restless, who is jumping all around the place.

Andrew Denton: Do you have nights sometimes where there are multiple patients who are difficult patients, where you are run off your feet?

Fran: Yes, we do, quite often.

Nancy: If you were here last night, we were run off our feet.

Andrew Denton: With her is registered nurse Nancy. She's called these wards home for 11 years.

Nancy: I got someone trying to get in and out of bed. It's a high falls risk. Then I got someone dying in another room, and I got someone who was quite short of breath and coughing quite a bit last night and needing a bit of attention. So nothing like this, like tonight. It was so busy we didn't have time to sit down.

Andrew Denton: As we speak, I can hear the occasional unearthly moan from somewhere in the ward. It is unnerving and I think to myself: So this is what dying sounds like.

Andrew Denton: Are you surprised sometimes at the tenaciousness with which people cling to life?

Fran: Absolutely, yes. They'll do anything to be here for another day, to see a grandchild who is coming in a week or an anniversary coming up. You can see them pushing to live.

Andrew Denton: Like everyone here, Fran and Nancy have witnessed the extraordinary human moments that occur in the final days of life.

Nancy: Just a couple of years ago we had a young woman here who was diagnosed, obviously, with a terminal illness. She wanted to be married before she died, and we sort of managed to get her that wish. She knew she only had a week or two left, so she brought her wedding forward. She already had a date. Funnily enough, after she had her wedding she deteriorated very quickly. They had their own – just like a hens party in here, but it was just sitting together at the bedside and all that. After the wedding they managed to stay in one room, with the husband staying in there for the wedding night as well. It was lovely. It was like almost a big ceremony for us as well, preparing her for the wedding, making sure that her lines were not going to show out of her dress. She had full make-up.

Andrew Denton: By the lines, you mean the medical...

Nancy: She had some subcut lines, like when we give them medication. We made sure that she had this medication before she goes down so that we wouldn't have to interrupt the ceremony.

Fran: It was lovely. She was only 28 or something.

Andrew Denton: That's a beautiful story, but I also find it kind of heartbreaking.

Fran: It was.

Andrew Denton: The balancing act required to work here – of being empathetic to your patients needs, but of not being overwhelmed by them – is quite something. Even so, it's not always possible to keep a lid on emotions.

Fran: I find that when people die at night-time and the family are leaving, that will bring me to tears. They give you a hug and say, "Thank you so much". It breaks me up sometimes.

Andrew Denton: I asked Fran how they help people who are afraid of dying.

Fran: Depends. A lot of people are afraid of being in pain, so we tell them that we can help them with that. They don't want to be alone. We help them with everything.

Andrew Denton: What's everything?

Fran: Everything they need. You know, if they have lost control of bodily functions, we can help them there, but they want to keep control of something else. A lot of people don't want to take morphine, because they think that's going to kill them, but everyone here explains it all in a good way, don't we?

Andrew Denton: I get the sense that that is important for a lot of people – to have some control over what happens at the end of their life.

Fran: Absolutely, because they have lost control of everything else.

Andrew Denton: We're used to seeing people die in the movies with a gentle sigh or a heroic look. In real life, it's not like that. The human body breaking down is a complex business.

And I'm starting to learn that words that mean one thing to the rest of us, in the language of palliative care, take on a completely different meaning.

In here, being restless doesn't just mean you have trouble settling ... it means you are writhing, sometimes thrashing around. Shortness of breath doesn't just mean puffing when you walk upstairs ... it means struggling for every single breath you take, simply while lying down.

Having seen it all, Fran and Nancy know what they would not want for themselves:

Nancy: I think shortness of breath would be my worst nightmare. It's just that the feeling of suffocating and not being able to breathe is quite scary.

Fran: I think I would like to be knocked out if that were happening.

Nancy: Yes, but what would be your worst symptoms?

Fran: That would be. Not being able to breathe would be the worst thing, yes. But looking after the worst, I don't like vomiting. I hate vomiting.

Andrew Denton: But you're a nurse! You're meant to be good at that.

Fran: It's awful. You haven't seen the vomit here. Some of it's horrible. It's huge. It's just everywhere, and that I don't like to see. But for me, breathing, you're right. Shortness of breath would be the worst thing.

Andrew Denton: It must be very confronting as a nurse when you see a patient who is not responding to medication.

Fran: It is, and sometimes that's the doctor's order. They are not ordering enough, and we have to ring them in the middle of the night to get them to order something, because nothing's working.

Fran: Some people are in excruciating pain at the end, and the family is watching, so we have to get the right medication for them.

Andrew Denton: That's a very difficult situation diplomatically for you guys, I would have thought.

Fran: It is.

Andrew Denton: That's a very diplomatic answer!

Is there a small sense of loss each time somebody dies, or is it the opposite – a sense of “We've done our job well”?

Nancy: Yes, I think it's the opposite. It's just like you've done your job. But there's also sometimes a sense that you feel, when they didn't die a nice death, like you have not achieved what you wanted to achieve by giving them the most dignified and comfortable death, not because you didn't do your job properly but because some symptoms are really difficult to manage, regardless of what medication you use or whatever intervention you try, and they die in that state.

Andrew Denton: Do you ever have patients in that situation ask for help to die?

Nancy: Occasionally, yes. They say, “Why can't I just die now? Why can't it happen soon? How long have I got left?”

Andrew Denton: And how do you respond to a request like that?

Nancy: It's a difficult question to answer, but you just have to give them the reassurance that they are not alone. We are here to help guide them through their last days and give them the assurance that they will be as comfortable as they can be.

Andrew Denton: As Nancy said, you sometimes wish you could do more. Is that also common in your experience?

Fran: It does. It happens, not very often, but there are some for whom nothing works, and it's horrible to watch, yes.

Andrew Denton: I would imagine that is the toughest part of your job.

Fran: It is. When we've got them nice and comfortable and that, that's all lovely, but it's when we can't control their pain or their angst – and a lot of people get terminally restless. It is not nice to watch. They just struggle the whole time, and you do wish you could do something, but there's nothing you can do, really. Nothing works, does it?

Andrew Denton: Do you get people who ask you sometimes, “Please help me to die. I'm ready to go”?

Nancy: Not many.

Fran: No, maybe one or two.

Nancy: One or two, but it's very rare. Maybe it is their understanding that they are here to die, so they don't ask, but there are people who very occasionally would say, “Help me. Just give me something”.

Fran: “I can't stand this. Just give me something,” but, you know, you say, “No, I'm sorry. We can't”.

Andrew Denton: The compassion and skill of the staff at Sacred Heart is something to witness. They are deeply engaged, not just with their patient's needs, but those of their families as well. To support this, a team of specialists – including dieticians, occupational therapists, psychologists, speech pathologists, chaplains, and physiotherapists – are on standby.

They include people like Ken Webb, who gave up a corporate career because he wanted to do something for the soul.

Ken Webb: I'm 23. No, I'm not. [Laughing] I'm 48, and I am the nursing unit manager.

Andrew Denton: Ken makes sure all the systems are working properly to help care for the 35 or so people who are typically on the ward. He likes that Sacred Heart was on the frontline in dealing with HIV that ravaged Sydney's gay community in the 80s.

Ken Webb: I liked the contrast of a Christian organisation they do not necessarily agree with that lifestyle, but when some of that group of people became vulnerable and their lives were being devastated, they were in the front of the queue saying, “Come in”. They opened up all the beds – I think we had 100 beds at one stage. I am proud to be associated with an organisation that has that dexterity.

Andrew Denton: Like most of the people I speak to here, Ken is very welcoming if a little wary about my agenda.

Ken Webb: I think one of the interesting things is there has been a lot of suspicion around why someone would be coming up here to rock the boat or be asking at all to rock the boat.

Andrew Denton: What makes Ken different to most of the people I met here is that he is upfront in his support of assisted dying.

Ken Webb: There are two people having this conversation with you, and that is somebody who has a personal belief about assisted dying and then a respect for the organisation that I work for.

Andrew Denton: That's an interesting thing. Assisted dying, euthanasia – how much is it normally discussed within this profession or within this place?

Ken Webb: It's not. It's not proactively discussed, but then there are patients who will ask or relatives will ask, and they will raise it and usually it's talked down. Like the times I have seen it: "We don't talk about that here". Or "That is not an option that we explore," you know. People are polite about it, but they close it down. Not because we work for a Catholic organisation – my most recent memory of that conversation was at the Prince of Wales. It is just not entered into.

Andrew Denton: Assisted dying is not legal in Australia, so perhaps it's hardly surprising that it's not discussed in palliative care. But the fiercest opposition to it, around the world, comes from the Catholic Church, so resistance to it here at Sacred Heart comes, for many, from a very deep place. That's why I'm all the more impressed at being allowed in to talk about it.

There is no question there is exemplary and extraordinary care here, but there is that percentage of people that can't be helped because people die differently and people are different. How difficult are those sort of cases in a unit like this when they occur?

Ken Webb: My personal views might conflict with – in terms of assisted dying – with the organisation, but I believe in the organisation's mission and values. So I think we do provide dignity and good care and the majority of the time symptoms are managed well. But there are occasions when a symptom isn't controlled or someone has a rough journey, for whatever reason, you know, and you do think about that.

Sometimes I wish people were unconscious before they were not able to swallow and they started being incontinent, because I mean the loss of dignity involved with losing control of those functions, of no longer being able to nourish and nurture yourself and talk and communicate – I wish people would just be unconscious earlier sometimes.

It is the chronic, long, slow death that can really be awful. There must be a point where you should be able to say, "I have no quality of life, I am now not able to care for myself, not have meaningful interactions with people". For myself, for my family, for my loved ones, I would want them to be able to exit when they wanted to.

Andrew Denton: You have probably almost defined the moment where, if those people are competent, it seems reasonable that they should be able to request something which means they do not have to die that way.

Ken Webb: Well, to be honest, probably the reason I want them to be unconscious earlier is so I don't have to see their loss of dignity, but also so that I don't feel discomfort about their discomfort. You know what I mean, like if somebody is a very proud person, and they are suddenly required to wear a nappy because they're bedbound, but they have still got all their brain happening, that is when I think it would be better if they were unconscious. I don't have

any problem washing someone, being involved in their care and make them feel better about it, but when somebody – it is so horrible.

And I don't think that is a reason to euthanase somebody. And we would never medicate them to be unconscious – just to be clear. Just sometimes it is a relief when they are slipping in and out of or into unconsciousness.

Andrew Denton: The term “death with dignity” is a live one in the debate about assisted dying. Nurse Therese Compton has her definition.

Therese Compton: So, death with dignity is that the person who is dying feels very at home within themselves. All the existential angst is gone, the big questions, the mistakes they've made and the achievements. Everything, you know? All their regrets, they've come home to a place of peace about it. And their symptoms are very well managed – they're comfortable. Very beautiful to see family around, like loving family around. They've come home to a sense of their own spirituality. And so all those things connected is dying with dignity, I think, yes.

Andrew Denton: It's a loving definition. But if you're that patient in a nappy, no matter how loving your environment, it might not feel like dignity to you...

Philip Redelman: I think if they are desperately ill I will make them comfortable. I'd like to think that that's what I do well.

Andrew Denton: Dr Philip Redelman is a visiting medical officer at Sacred Heart. He immediately got my attention at the weekly team meeting with his frank way of speaking.

Philip Redelman: Look, I am realistic to know there is a small percentage whose pain we never get control of, there are people who have anguish and things like that, and we try work hard to do it. And I don't mind giving people more and more drugs if that makes them comfortable. I'm quite happy to do those things. I say to people, “If you like, I can offer you medications that may make you drowsy and more peaceful. Would you like that?” But my aim is for their comfort and it is not to end their life. I separate in my own mind my thoughts and it is very clear that I don't believe I have ever prescribed a drug with the intention that this will end their life.

Andrew Denton: Do you think you have done that and unintentionally ended someone's life?

Philip Redelman: OK, hold on. So the drugs I give people I am well aware may end their life, but it is not my intention.

Andrew Denton: Philip has just given a short master class in what is known as the Doctrine of Double Effect – a way of thinking introduced in the 13th century by the Catholic philosopher Thomas Aquinas.

What it means is that if you are tending to someone who is dying, you can give them medication which may have the unintended effect of helping them die more quickly but only if your actual intention is to ease suffering. What you must not do – ever, because only God giveth the hours and only God taketh away – is give them medication with the intention of helping them die. Even if only death will end their suffering – and even if the patient is begging for such relief.

Today, that idea is boiled down into the central tenet of all palliative care: “We will neither hasten nor prolong death”.

I'm fascinated with this and I'm really interested to hear you say how do you work that out in your head?

Philip Redelman: Well, for example, there was a patient who obviously was a doctor. The son was a doctor, who was a neurologist, and she was having a fit, and he was there too. So we wanted to stop the fit so we gave some IV dex– Valium – that's fine. You give 10. That didn't seem to stop it. So you gave 20, which is now getting a big dose without resuscitation equipment. And didn't stop fitting. So then I looked at him, he looked at me and we gave her another one.

Now that is really being a sportsman but you have a high risk that they may stop breathing. But that was never our intention, and so I think you can have – you might say you take risks but you do things for comfort care, with the consequence that I know that sometimes people can die from that. But my intention has never been – I have never drawn up a dose and said, “Give them that,” which I believe would 100% shorten their life – not shorten their life, kill them. I have often drawn up doses that I think may shorten their life but they need it for their comfort care, and that has always been my intention.

I will give everything to relieve their suffering. Not to be mean. I would take the risk for them that they might die, fair enough, but I wouldn't hold back saying with my thoughts, “Oh I might kill them”.

Andrew Denton: It's such an interesting Chinese wall that you build in your own head.

Philip Redelman: Well, mate, we do. That's the only way we can survive too. That might be how we think and that's what we do.

Andrew Denton: What does this mean in practice? Because people die differently it means different things.

For most patients in the expert hands of a palliative care team, medication delivered with the intention of easing suffering, but not to hasten death, is sufficient. Their pain is controlled, nature takes its course, and they die “a good death”

For a small number of patients, with particularly difficult symptoms to manage – agitation, existential distress, shortness of breath – the only way their symptoms can be controlled is by terminal sedation, a slowly-induced coma which, if managed right, you will not wake up from. It has been dubbed “pharmaceutical oblivion” and even this can't address all suffering.

And for that ‘small percentage’ whose pain, as Philip said, they can “never get control of?”
Therese Compton.

I have no question that you do everything you can to manage pain, but not all pain can be managed.

Therese Compton: That's right. That's right.

Andrew Denton: Even Palliative Care Australia says that.

Therese Compton: Yes, that is right.

Andrew Denton: When you reach those cases and there is a limit to how much pain relief you can give – because you do not want to be intentionally ending someone’s life – how do you deal with that?

Therese Compton: Dr Chye would tell you that that is probably only about 4% of pain that you cannot manage, and I have only seen that in Sacred Heart about three times in 10 years – and that is difficult. It's extraordinarily difficult, and you feel at your wits end. It is difficult, yes.

Andrew Denton: That small number – 4% – of people whose suffering is beyond the reach of even the best palliative care can offer, squares with the numbers from overseas, where those helped to die make up a tiny percentage of the population. In Australia, we offer that 4% nothing, primarily because the law forbids it – but also because a religious idea from 800 years ago still informs our medical practice. Yet as Belgium, a predominantly Catholic Country, has shown, it is possible to find a way for 13th century religious thinking to sit alongside 21st century medicine.

Andrew Denton: I spoke to a beautiful man in Belgium called Arsène Mullie, who is a senior palliative surgeon there – physician, and their euthanasia laws came out of their palliative care system, and he said his philosophy is: “If the patient sees there is no solution and I as their doctor see there is no solution other than death, how can I not help them?” Why is it not possible to have that philosophy in practise here?

Philip Redelman: I just see that as murder; that's all I can say. I wouldn't be part of that, I just couldn't be part of that.

Andrew Denton: Even at the patient’s desperate request?

Philip Redelman: Yep, that's right.

Andrew Denton: Palliative Care Australia acknowledges that there are some patients who persistently and rationally request a hastened death. They say the numbers are few. Beyond the law, Philip Redelman offers another reason why this might be.

In your experience, how common is it that people request a hastened death?

Philip Redelman: Look, you have to understand that it goes something like this in the hospice – you meet people and they say, “I wish it was over tomorrow”, and they say, “But you wouldn't do that anyway”. I've already got my excuse before I even open my mouth.

Andrew Denton: That is true though, isn't it?

Philip Redelman: Well it IS true. We don't do that. Once you come into hospital you lose control; you can't do anything about it. We are in a unit where we see 50 patients. Last week it was exceptional – there were four; normally it is one or two, so it is not a high thing that we see, but there might be a bias in it. Already they're thinking about that we won't do it, so why bother wasting their breath?

Andrew Denton: Why should a competent adult who is dying who requests help to die quickly be subjected to a slow death?

Philip Redelman: I guess maybe it might be because the doctor isn't going to do – you know, shorten their life in a way. I just – I guess I say in some ways that's their destiny. Your number's up, your number's up. I'm sure I can tell you of cases where within that slow death there was good came out of it, even though I would never – kind of it's hard to rationalise that, but I have seen families pull together, and it has been good for the families. But still I understand that it always is a slow death. It is just as hard sometimes for the doctors to go in each day and you think, “How can this person still be alive today?” But that is how it is, and I'm not going to change the status quo.

The people I am thinking about are the people who just get weaker and they lapse into a coma but they don't die straight away,

You shouldn't colour it with saying they had great pain and things like that, because that's not good.

Andrew Denton: No, no, no, I'm not suggesting all patients.

Philip Redelman: Can I say – I don't think it's the patients that are suffering. I think they are unconscious.

Andrew Denton: That is certainly not the testimony I have had.

Philip Redelman: Isn't it? The most problems I get is with the families. They say, “If it was a dog, you would shoot him,” and it is just that the family are so distressed that this person keeps lingering on.

Andrew Denton: I don't doubt, for one second, Philip's position. Ninety-nine times out of 100, if I were dying, I would want him in the trenches with me. But if I were that 100th person? Part of that 4% whose suffering they can't get hold of? What's it like to be one of them?

Spencer Ratcliffe's partner, Deb, was 50 when she was diagnosed with adeno carcinoma and, later, the lethal lung cancer, mesothelioma. After 43 cycles of chemotherapy, her fight for life led inevitably to palliative care, at another hospital in NSW. But in Deb's case medication was no match for the searing pain of dying.

Spencer Ratcliffe: I'll give you an example of one night which was probably in the last 10 days of her life when I was on night duty, so to speak, with her. The doctors can only administer, as you would know, morphine – certain amount over certain hours otherwise that can put the patient to sleep permanently, and obviously that's not allowed. So as much as the patient may want that, the doctors are understandably – and nurses – scared stiff of overdosing their patients. The pain was getting so intense on this particular night that Deb sort of called out to me and said, “Spencer I need to walk. I must walk. I've just got to do something” We walked around the corridors of this hospital for six hours until she was allowed to have more morphine and during those six hours – I've probably still got the marks – her nails were clawed into my back through sheer hell.

We just walked past doors wherever they were leading into, you know, utility rooms, and she'd just scratch at the door. She had to do something to alleviate, the horrendous pain she was in. I've never seen pain like it. I've been a journalist for 49 years; I've seen people in pain all over the world in wars and whatever else. I have never seen anybody in such pain that she was in that night.

Andrew Denton: What kind of pain relief did you ask for? Did you speak to the nursing staff and ask for help?

Spencer Ratcliffe: Constantly, constantly. That little red buzzer that you press, my finger was on it almost all the time, and of course they are busy people, the nurses, especially on night duty, so I was forever walking out to the nurses' station looking for nurses, searching for them.

Andrew Denton: Why were they reluctant to provide extra pain relief?

Spencer Ratcliffe: Because they were scared that they would overdose her.

Andrew Denton: Did they say that directly when you asked them?

Spencer Ratcliffe: They said we can only – we're not allowed to give any more for another two hours and 14 minutes or whatever. It's all written down on the chart. "Why not?" I'd say. "Because that's the amount," the doctor says. "We're not allowed to give any more than that." "Why not?" "Because it's the legal limit that we're allowed to give." She was only allowed a certain amount every hour or two hours or whatever.

But because the pain just keeps growing and growing and growing, but the amount of morphine grows too but not in accordance with the pain. It's very hard to measure that, but you can tell when someone's screaming in pain and they're just crying. "Please can she have some more?" "No". I said "How can you just tell me that? How can you sit and watch her in such pain and tell me she can't have more morphine?". "Because the doctor says I can't".

Andrew Denton: Did you ask directly for them to do something more?

Spencer Ratcliffe: Yes, I did. I asked directly one night to the head of palliative care. I took him aside and I said, "Look, this is crazy. You can see the pain she's in. What can you do to help her?" is how I worded it, because I knew how delicate the conversation was. "We can do no more than we are doing, Spencer". And I said, "You know, what are we supposed to do? Just sit and watch her scream herself to death in pain?" and he said, "Well we're not allowed to do any more. Euthanasia is not legal". And you just shake your head and go, "What the hell can you do?"

Andrew Denton: Did she at this time express a desire to be put out of her pain?

Spencer Ratcliffe: She did. She did. She said, "Spencer I don't want this anymore". And that's when she said, "Can you find out for me what's necessary to take?" and I did. I said I had it and she said would I help her, and I said I can't do it. I just couldn't do it.

Andrew Denton: Why couldn't you do it?

Spencer Ratcliffe: Because I loved her. So where's that line between loving someone so much to put them out of pain and loving them so much that you can't put them out of pain. For three years I'd thought about it, but when you get there it's a different thing. It's a different world entirely, Andrew, and I still will probably never know whether that was the right answer or the wrong answer. But what it did make me feel was everybody – every doctor in the hospital knew she was dying. She was in the room where you go before you die. Should a relative be left to do that? You know do you put a paper bag over someone's head? Do you inject them with something? Do you shove tablets down their mouth?

Andrew Denton: How hard do you think it is for nursing and medical staff in that situation to see somebody clearly in excruciating pain but the rules tell them they can't help them, much as they need it?

Spencer Ratcliffe: I think it must be horrendous for them. I would think they must go home at night and never bloody sleep. And all they want to do is perhaps help, but they can't. They've got their hands tied behind their back because of the law.

Andrew Denton: With days left to live, Deb demanded to leave the hospital so she could die at home. As I listened to Spencer's anguished retelling of Deb's last days, I thought of the way they help people die in Oregon – the way, I had increasingly come to believe, we should adopt here – which is where someone like Deb is legally prescribed life-ending medication that they can choose to swallow or not. No doctor needs to be involved at the end. It is entirely the patient's choice. I asked Spencer if he thought that would have worked for Deb.

Spencer Ratcliffe: Absolutely. Far better. If she'd been able to take a drink that could have put an end to it all, I have no doubt she would have done so. I have no doubt at all.

Andrew Denton: So why is the acceptance I found within the medical profession overseas – that palliative care and assisted dying can work together – so hard to find in Australia? Perhaps it is partly to do with the information they're getting. I asked Ken Webb if there was any understanding of what happens in places like Belgium or the Netherlands or Oregon.

Ken Webb: From a personal perspective I thought I knew a little bit, a bit, and then talking to your producer, Bronwen, I realised how little I knew. In general I think we are informed by media and sort of the very dramatic situations of someone having treatment removed and that somehow being construed as euthanasia, and it is all that sort of stuff that informs our knowledge, so I don't know.

Andrew Denton: If you want to take the most conservative example – Oregon. The conditions are you have to be terminally ill with six months or less to live, in intolerable pain. Two doctors have to agree on that, you have to make an oral and a written request, you have to have all your options discussed with you – palliative care, all the other options – plus you need to indicate that you fully understand what it is that you're asking for. Then 15 days later you have to reapply for that process, and then if the doctors agree that you meet the medical and all the conditions, then and only then, will you be written a prescription for the medicine, which is entirely up to you to take, and 40% of people that are given it don't take it, which tells you a lot. The percentage of people who die in Oregon, to whom this law has applied in the 17 years it has been going is less than 1%. It has never changed.

Ken Webb: Wow! I didn't know that. I mean that is what I assumed would happen. When you talk to people about having the option it is about having the option, not about taking it. And from what you're saying people don't necessarily go there.

Andrew Denton: Well ironically they have discovered that almost the greatest benefit of assisted dying medication is it is in itself palliative. It removes anxiety. It allows people to focus on those things at the end of their life which we would all want to focus on – our own thoughts, our own families, our own farewells, the existential questions, without being in a panic about what is going to happen at the end.

Ken Webb: I get that. Personally, I would like to have that option in my drawer. I might not ever use it but it would be comforting to me personally.

Andrew Denton: Philip Redelman's understanding of how the laws work overseas was even more revealing.

Philip Redelman: But overseas, right, once – I don't know how they do it, I haven't looked at the fine details or anything like that – but if you're a palliative care doctor and you worked in a hospital and I said to them, "Here is the bit of paper that says it's OK, the legal document," like that, then the nurses would say that's fine. If you wrote it, they would give it.

Andrew Denton: No. No, that's not how it works.

Philip Redelman: They wouldn't...

Andrew Denton: No, no. First of all, the nurses can't do it. It takes two doctors to sign off on it...

Philip Redelman: Yeah, alright.

Andrew Denton: And it happens over a period of time. It is not like a two-week thing, and usually what they find with this is they spend a lot of time with that patient counselling them, and one of those doctors is almost always their family doctor so they already know them. So it is never quick, it is never easy, and it is never done easily.

Philip Redelman: OK, fair enough. Well what about the person with some dementia – they are not mad, and the family say, "Look, I think this is a good idea," and things like that. "Look, Mum, things are tough at home". How does that happen over there? What protection do they have there?

Andrew Denton: They have to be able to competently request it and the doctor – and more than one doctor, and in the case of psychiatric in Belgium it is three doctors have to sign off – they have to agree that this person is competent, this is a competent and rational decision. So it is not an advanced directive that they read five years later and just knock them out.

Philip Redelman: Fair enough. I mean you just need such guidelines.

Andrew Denton: And they have spent years, the medical profession, working out these guidelines. And yes, there are people who have strong moral objections who will not

participate, and that is as it should and will always be, but it doesn't mean the system isn't very carefully thought through, and there are a lot of safeguards.

Philip Redelman: Maybe it is working, but in all fairness, I haven't studied this recently or anything like that. That's really the situation.

Andrew Denton: The reason I raise it is because it was doctors in the Netherlands that designed the system there, it was palliative care doctors in Belgium that did it, it was doctors in Oregon who took a neutral position – so didn't oppose it but made that law possible. So it feels to me that doctors such as yourselves, who don't ever need to agree with it, nonetheless, is it not your duty to perhaps pay closer attention to what the arguments are so that you can say in the end, “Look I take a moral stand and I don't agree with it, but I realise that these slippery slope arguments are not necessarily true, that it is possible to create a system which is policed”?

Philip Redelman: I guess that's right, at the end of the day, but when it comes to looking, well, I will look a bit harder, but at the moment it is not high on my agenda of topics.

Andrew Denton: The men and women who work in palliative care are asked to provide services that are so much more than purely medical. That's because dying is more than a medical experience. It's spiritual. Existential. And – ultimately – deeply personal. Two things struck me about the doctors and nurses I spoke to at Sacred Heart – one, their deep commitment, and compassion towards their patients, and two, the universal acknowledgement of how hard they found it when a patient was beyond their help. It seemed to me that if they understood better how their counterparts overseas had embraced a way to assist those unfortunate few to die, they would not be so resistant to the thought of doing the same here – or at least allowing others to.

But the deeper I dug, the more I found that this resistance was not only implacable, but its implications for some patients deeply troubling.

Next episode, join me as I talk with the director of Sacred Heart, Professor Richard Chye, and ask: Whose life is it anyway?

Ken Webb: Personally, I would like to have that option in my drawer. I might not ever use it but it would be comforting to me personally.

Andrew Denton: Well I have decided after being here just for a week that I want to be hit by a comet while having sex.

Ken Webb: [Laughing] Yep, we'll arrange that for you.

[CLOSING CREDITS]