

Episode 12 – Velvet Ray

[SUICIDE WARNING]

[PRAYER BELL CHIMES]

[ETHEREAL FEMALE VOICE]: **There is no death. There is only me, me, me who is dying.**

Ray Godbold: I've decided that with the experience I've had in my life that the only way that I can manage my own death is to become quite active and take things into my own hands and not have a stranger come into my life in the last 24 to 48 hours dictating what I should and shouldn't be doing as far as my own death is concerned.

Andrew Denton: Ray Godbold is a palliative care nurse faced with terminal cancer. But he doesn't want to die in palliative care.

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

[OPENING TITLES]

Andrew Denton: My name's Andrew Denton. You're listening to *Better Off Dead*. And this is the story of Velvet Ray.

Ray Godbold: My name's Ray Godbold. I only get called Raymond when I'm in trouble. I'm 59 years of age, turn 60 next January. I've been a registered nurse for 34 years, and gradually at the end of my career I graduated towards cancer care and the palliative care field.

Andrew Denton: Ray earned the nickname "Velvet" from a patient grateful for his gentle way with the dying. Now Ray is dying too.

Ray Godbold: I was working as the clinical nurse consultant for Darwin city in May 2012 when I was diagnosed with stage 4 cancers.

Andrew Denton: There had been no symptoms. Just a bad bout of indigestion. But there it was – an 8 cm tumour that started in Ray's stomach, moved to his oesophagus, and was still on the move.

Ray: He pulled the scan up and he said, "There it is. It's in your liver already". So once it's spread, you're not an option for surgery, which is the only curative measure you have.

Andrew Denton: It's March 31, 2015 and I'm sitting in Ray's backyard in the Victorian seaside town of Inverloch. There's a lovingly-tended vegetable garden that backs on to the bush. Birds are everywhere. Ray, a tall man with a dry sense of humour, tells me about how he first met his wife, Robyn.

Ray: It was a very hot day and at the end of it there was a dam there and we all went skinny-dipping, and I must say she caught my eye then.

Andrew Denton: Was that a similar moment for you Robyn?

Robyn Godbold: Probably. I can't remember – I don't...

Andrew Denton: I think you're obligated to say yes.

Robyn: Not as vivid as Ray's memory, but yes, definitely.

Andrew Denton: They've been together for 33 years. Robyn, too, is a nurse. Has been since she was 17. I wonder if it's a good thing to know so much about what they're facing.

Robyn: Yeah. I think it's – from Ray's perspective it's given him this sort of calmness about it all and a very intellectual approach I suppose to it, which has been really nice. It's helped us a lot.

Andrew Denton: Ray's illness sounds like everybody's nightmare.

Ray: See, the other problem I have – I'm perfectly healthy. My lungs, my heart, my liver and my kidneys, even now with this disease process inside me, are all within normal range, so that's just going to prolong... To achieve death that's what you need to happen is for your organs to, you know, to cease.

Robyn: He knows – we all know that his prognosis is very poor and that at some stage he will deteriorate and he's not going to have a long life.

But I suppose being nurses, this is how we're compartmentalising things a little bit, so we're just trying to make it enjoyable now and not worrying about what's ahead, but we are having in the back of our mind – like Ray's made plans and all that sort of thing.

Andrew Denton: Despite being a palliative care nurse, Ray's plans do not involve dying in palliative care.

When did it become clear to you, Ray, that you wanted to take control of your own death?

Ray: When I got home and I started thinking about my situation, because I've had so much experience with other people dying and sometimes there is no total control of somebody's death. You know, there's ways and means that palliative care administer death and that being slowly with what we call M&Ms – the morphine and the midazolam scenario, and one quarter of all people with advanced cancers die from a catastrophic event like a huge bleed, a heart attack, pulmonary embolism, pneumonia.

And then I realised there's quite a margin of error for something to go amiss, you know, because we are in the country here and I haven't got the full facilities of being in a large centre, you know?

So I came to the conclusion that I should have a bottle of Nembutal on my shelf and see what happens, you know. It would only be used if I was suffering intolerable pain, and that could even be psychological pain. I would never ever use it lightly but having that reassurance that I don't want to be dependent and I don't want my family to have any trauma with my passing, because I don't think there needs to be. I think it can be quite peaceful and comfortable.

Andrew Denton: Was it an easy conversation between the two of you about Nembutal and taking that step?

Robyn: Nurses tend to, because they see some not so nice things happen. But it's different when you're discussing it as this theoretical thing in the future to when it's actually something that, you know, could happen any time.

Andrew Denton: The illegal drug Nembutal will offer Ray a painless death. But in answering the question of "how to die" it asks an even bigger one: "when to?"

For me that would be the cause of greatest fear – that despite your desire to control what happens you may not be able to.

Ray: The timing of the Nembutal is going to be very important for me because, like I say, I don't know which way the disease process is going to go, with having perfectly healthy organs.

Andrew Denton: It strikes me that you have a very difficult choice ahead of you as to should you take action and when do you take action.

Ray: Yeah, exactly, and this is the nutshell of the whole argument. We're forced to make choices right through our lives until we get to – the other most important thing in your life is your death, where those choices are taken away from you, and this is what the whole argument is about.

Andrew Denton: Ray calls the Nembutal his "back pocket plan".

Andrew Denton: When you get the Nembutal home, where are you going to put it?

Ray: That's a good question. It's a very good question.

I'm not telling you.

Robyn: [Laughs]

Andrew Denton: [Laughing] I'm not going to come and take it!

Ray: No, I know you're not. I'm going to keep it at a friend's house. I've got one confidante out of my family group. Because you need to have another person outside your group.

Robyn: We've got children running around the house, so that's a consideration.

Andrew Denton: Why not here though?

Ray: Just in case we get raided early.

Andrew Denton: Ray's decision to source Nembutal means he has to allow for the possibility that the police will want to investigate his use of an illegal drug.

Ray: So that's the other thing – if I was to administer that medication to myself that my family wasn't present or had knowledge of that.

Andrew Denton: How is it for you, Robyn, that you may not be able to be there to farewell Ray?

Robyn: We'll be there. I'll be there.

Yeah, I want to support him in his – I believe in having a choice. I don't want to sit by the bed for days, 5 days or 10 days – he will get to a stage where he won't be able to swallow or eat or drink, and where he is in the disease process when that happens, we don't know.

Ray: No, that's it.

Andrew Denton: In the debate about assisted dying in Australia, Ray Godbold's voice carries extra weight – a palliative care nurse who doesn't want to die in palliative care. I wondered why.

Andrew Denton: Ray, in your line of work as a palliative care nurse, you would have seen people go through this disease.

Ray: Yeah. I've looked after people with both stomach cancer and oesophageal cancer. If I was to choose a cancer to have, I wouldn't pick this one.

Andrew Denton: And Ray, you working in palliative care, did you also have a strong view about euthanasia?

Ray: Yeah well I did personally, but it's not something that you would voice when you're working in the palliative care field. You know, I think everybody – if we all sat down on a Friday night and had a few drinks together and people were honest on what their beliefs were, a lot of them would come out and say, "Look, that was a shocking death, we should have done something else to help," you know. But you've got the legal boundaries, the medical professional boundaries are all, you know, they've got you surrounded and you can't step out or be seen to step out because the next thing you could be accused of using excess morphine or...

But my own personal belief was that I fully supported it because I've been there when lots of people have had terrible deaths that – no matter what palliative care people say, the last 24 to 48 hours of somebody's life can be completely unexpected, you know? And the only options you've got is to make that person unconscious and then you've got the family's sitting there looking at this person who's been in terrible suffering, is now unconscious, and is going to take hours or days or weeks to die. So that's not acceptable I don't think.

Andrew Denton: I asked Ray if there was one particular death that stayed with him.

Ray: The one that sticks with me the most was a gentleman who had existential distress, and he was definitely going to suicide. And he had a very similar cancer to mine actually.

He came into the hospice and he made it quite clear that he was going to kill himself. So they decided on terminal sedation for him, and his wife sat beside his bed for five days. Five days it took him to die, each day having little increments of his morphine and midazolam and his haloperidol, you know – what they could legally give them. You're just waiting for one of his organs to fail – like for him to have a heart attack or respiratory arrest or something like that, but five days is a long time to watch someone die, you know, and to just administer medication. That happened in the hospice.

That's where I think voluntary assisted dying would have been of great benefit, because I was very close to this gentleman's wife, you know, because I'd been supporting them at home for quite a few months, and to see her on a daily basis slowly getting worn down and worn away by sitting there and being a devoted wife, you know – they'd been married for 50 years or something like that...

Robyn: And that final memory of that person, it can be hard to obliterate that. What you remember of that person is that last moment. That might be absolutely awful, whereas if they have a more controlled death, then the final memory won't be as traumatic, so you won't have to deal with that side of it.

Ray: See this goes against the palliative care philosophy that you should not hasten death, but that's exactly what the whole situation was – hastening his death. But it took so long for him to die that I think he was the perfect candidate for active euthanasia.

Andrew Denton: The guiding philosophy of palliative care Ray was referring to – to “neither hasten nor prolong death” – continued to puzzle me. If people die in such unexpected ways, how do doctors know the line to tread between easing somebody's pain but not assisting them to die? Surely, in the end, it comes down to a doctors' judgement call?

Ray: It is, and it's totally unjustifiable, and that's where the doctors and everybody have to turn their back, because they are making that decision on the clinical information. Palliative care does a really good holistic admission to the service. They do. They look into your different – if you go to such and such church and you've got all this – they'll do their best to get the social worker in. But the last 24 to 48 hours with the terminal sedation, that's where I feel it all goes wrong, because you can't – it's up to the person themselves to let you know what is happening, and they put them in a position where they can't express yourself and give your decision because you're unconscious and you're waiting to fade away.

Andrew Denton: What did you mean when you said that's where the doctors have to turn their back?

Ray: “Thou shalt not hasten death.” Well you're looking at a person who's clearly dying, and say they've got morphine 30 and midazolam 5, in their syringe driver, the little green book tells them that they can only increase that by such and such an amount otherwise the clinical picture becomes too much.

Andrew Denton: Presumably that level of treatment, regardless of the guidelines, varies depending on the individual beliefs of the treating doctor.

Ray: Of course. There's still doctors that won't give the after morning pill to different people and the doctors have all got their own beliefs, and a lot of them have got religious beliefs, and that comes into the clinical area at times. I've seen it. You can't trust a man in a white coat.

Andrew Denton: I don't think I want to hear that!

It was to be two months before I saw Ray again, in early June. He was noticeably thinner but still, it seemed, very much in control of his life.

So tell me what's happening with your body.

Ray: Well slowly there's signs and symptoms the cancer metabolism is taking over control of my body, so I feel more of a patient now than a person dealing with cancer. I feel that, you know, it's still going to be weeks to months away, I hope, but I'm getting to that stage where I'll need more and more medical attention.

Andrew Denton: Is there a sense of being betrayed by your own body?

Ray: No, there's a sense of being cheated or robbed of a few years, you know. Because I had no indication at all that I had a GI tract problem. I was getting my lower end checked regularly and all this around you is in preparation for me – for my retirement – to enjoy my music, to enjoy the books, to enjoy the garden. That's what I've been striving for – that everything could be nice, you know. So yeah, I do feel robbed of 20 years I reckon. But that's part of understanding that we're only mortal and we're part of the coil that goes round. A friend of ours they had a little baby girl this morning at the Children's Hospital. I'm just making way for them. Yeah.

Andrew Denton: Ray's most recent visit to his GP had confirmed that all his organs were still functioning perfectly. This was not good news. To die, Ray would need one of his organs to fail – which suggested that the path ahead of him was going to be long and painful. I asked if he had a sense of when – or if – he might take the Nembutal.

Ray: Not a clear sense, obviously. My objective is not to use it, but I've got this alien in my stomach and it decides – the problem is once I cease chemotherapy altogether how malignant this alien is, so how quickly it wants to spread to my other organs and help me with the demise.

Andrew Denton: At what point is it right for you to stop chemotherapy?

Ray: Once I know that the drugs aren't working any longer and I say, "We'll stop it now".

Robyn: His chemotherapy is palliative chemotherapy, so it's not curing. It's just about balancing and making him more comfortable until the disease takes over. And it's helping with eating and that sort of thing. That's why he's having it. People think he's having active treatment, but it's not.

Ray: We live in hope that I don't cough one day and it is bloody.

Andrew Denton: Because that means you have to go to hospital.

Ray: It means that I have to take the Nembutal, because it's dependent on me hopefully having a patent GI tract for it to be effective, you know.

Andrew Denton: Of course, yes.

Ray: If I haven't got a patent GI track, the Nembutal, it's not in the game. I've got to get it into me as quickly as I can then.

Robyn: So the decision-making with this type of cancer that Ray's got is critical, if he does want to take it, because if he obstructs, then he won't be able to.

Andrew Denton: So how do you make that decision, because you can't foretell what's going to happen, can you?

Ray: No.

Robyn: You just have to go on the symptoms.

Ray: Yeah, when I physically really can't look after myself, when I become totally dependent on other people, and with no disrespect, I'm starting to look like somebody from Changi anyway, you know, during the war, and I'd be mortified if my kids saw me naked and had to look after me. That would mortify me.

Andrew Denton: You said earlier that you might not take it and that in fact – I think you said, “I hope I don't take it”.

Ray: I'm hoping not to, yes. I'm hoping not to, yeah. But like I said, I don't know. We've got to assess as we go from stage to stage, and I know that I'm slowly getting pushed along the line.

Andrew Denton: Ray and Robyn's children are Rory, 27, Tara, 32, and Ella, 30. As Ella explained, her parents were pretty well known in the district.

Ella Godbold: They have a big reputation in this community. They did work at Wonthaggi Hospital for 23 years together, and nurses are very social people. Like growing up, we'd always have a nurse end-of-year party here and it was always really fun and wild.

Rory Godbold: The rug would get rolled up at one stage of the night. I had a little position in the kitchen where I'd make cocktails for everyone. Dad would get a cocktail book and put all the spirits out, and I'd make it.

Tara Godbold: It was fun. They had lots of fun.

Andrew Denton: All the children support Ray's decision to give himself a choice about how he dies. This is Ella.

Ella: I absolutely understand where he's coming from and where he wants to be. He's been exposed to people dying and he knows the way that he wants to go out, and that's absolutely fine with me. I mean I know Dad's not going to do it too early, where he's still got stuff to give us, and I trust in his decision. Because that's what scares me is that time is taken away, but I trust that he'll do – he knows when the end is the end.

Andrew Denton: Tara gets it too.

Tara: One of the ladies at my work's mother had the same cancer. She was much older. But she wouldn't even talk to me about what happened in the last stages. She said it's still too distressing for her to be able to talk about.

So I've got a bit of insight from that as well, and then also – and we've had that conversation with Dad – about these are the scenarios, these are the certain things that could happen, and it's horrific. And we have to live with that as well. Like that's the thing. It's also not just

about him. It's about what we have to live with for the next 50 years as well, and I think in some ways it's a protective measure for us too.

Rory: It's interesting because I think Dad sees it as, "Thank God, I've got this for my family!" and we think well thank God he's got that for him if he wants it, like it's kind of crosses in the air or something.

Ella: And also he always emphasises that him and Mum make the decisions together. It's not just about him and what he wants, like they're kind of on the same page about it, and they will talk about it and make sure they're both happy with the scenario.

Andrew Denton: Are you proud of Ray?

Tara: Of course. Absolutely.

Ella: We will be proud forever, you know.

Andrew Denton: When I next saw Ray, only three weeks later, the change in him was shocking. He was painfully thin, moving slowly, bruises and cuts were clearly evident from multiple falls, fluid was dripping from his nose, and deep lesions were on his fingers, as though the cancer was trying to eat its way out of his body.

Ray: I've obviously deteriorated quite considerably and had three falls, but I've also got these wounds that are coming from the inside to the outside of my body, which are causing me great pain. There are splits in the creases of my fingers. It's another sign of progression of my disease. The first step is I get dyspnoea and then I get secretions.

Andrew Denton: What's dyspnoea?

Ray: Dyspnoea is difficulty breathing. And I've got SOBOE, which is shortness of breath on exertion. My voice changes, my nose drips – dah, dah, dah. Lots of secretions. They're coming out.

Andrew Denton: So your body is just falling apart.

Ray: Yeah, yeah, it's falling apart. Yeah, I'm dying. I'm falling apart really.

[FAMILY TALKING AND LAUGHING OVER LUNCH]

Andrew Denton: As I sat with the Godbolds at lunch, the good-natured conversation and humour was in stark contrast to what we could all see – a man almost literally disintegrating in front of our very eyes.

After lunch Ray told me that he'd just reached a critical moment in his treatment. He'd decided to have the intravenous line, or PICC, delivering his chemotherapy removed. It was a decision even his oncologist struggled with.

Ray: He looks after a hell of a lot of people in Gippsland, and he came out to the waiting room and he yelled out "Raymondo", which was highly unusual for him. So I went in there and Robyn was with me and we had the conversation and he was going to offer me whatever he could, and then I decided, no. And he turned around and he had tears in his eyes, and I was really quite surprised.

Andrew Denton: Just what does removal of PICC mean? Why was he responding to that?

Ray: It means that all treatment's over. That I would be purely in palliative, and that would be, you know, waiting for me to die.

Robyn: It's a little bit scary, really, I find. You know, the treatment...

Ray: Well it is, if you have no intravenous access to your body.

Robyn: And knowing that that's it. What's going to happen? How quick?

Andrew Denton: Because I remember you saying to me when we first met that once you decide to discontinue chemo that things most likely cascade pretty quickly. Is that still your understanding?

Ray: Yeah, well if I'm right. It's definitely a top-three malignancy – and then the way that it spread before I was even aware of it, you know. But I'm hoping that I get five to seven days from the chemo and then I get a period of time where I'm a little bit better – but that's a day - by-day hope.

Robyn: Yeah. You've got nothing left in the tank though. You've always had a little bit in reserve.

Andrew Denton: You're talking weeks though?

Ray: Weeks, yeah. I'm only talking weeks, yeah.

But as you can see, I'm really quite alert psychologically and I'm not ready to hop into bed and say, "I'm ready to die". So it's looking more and more like Nembutal will be an option for me, because I'm just going to starve to death otherwise and be in pain.

Andrew Denton: I guess that's the other part of the equation for you – how it is for the family?

Ray: Yeah, that's right, and that's where I've got to have that discussion with them, because it's purely not my decision. It's their decision as well.

Robyn: I sort of know that when we get to a certain stage it is going to be discussed, but ultimately it's Ray's...

Ray: Yeah, it's going to be harder. It's going to be harder than what I imagined but...

Andrew Denton: Why do you think it's going to be harder?

Ray: Because saying goodbye, leaving someone permanently is very difficult I think. I've always had my goodbyes but I've always had that, "But I know I'll see you in the future". But as you can see, I deeply love my family and home, so I'm going to find that a lot more difficult than what I thought. The pain, suffering, whatever that comes to, that's what it comes to, but making the decision that I have to permanently leave all this is going to be more difficult than what I imagined.

Andrew Denton: Despite the pain, and the awareness that his time is running out, Ray's focus is on something else – a tropical holiday.

Ray: Robyn's really keen to go to Palm Cove, and I'm keen to take her.

Andrew Denton: Tell me about the Palm Cove plan, Robyn.

Robyn: Well, when we first started going out, back in the 80s, on our first holiday we went up to Far North Queensland and we camped at Palm Cove and it was beautiful. And so we

just want to escape for a little bit and experience some warm weather. So we decided that we'd go back to Palm Cove.

Ray: Really I've got the one goal, and the goal is to get Robyn up north for a little while. And I bought my board shorts. The lady came to help me and she had to send me to the boys section to get my board shorts. I've gone from a 34, 36 waist to a 14B, whatever that means.

[CHILD SQUEALING WITH PLEASURE]

Andrew Denton: Watching Ray push his grand-daughter Ivy on a swing in the backyard I thought back to something he had mentioned at our first meeting – of how the dying sometimes struggled with existential despair.

Later, when it was just the two of us, I asked if he could describe what that felt like.

Ray: Just, I don't know – despite our conversation and despite everything that Robyn does for me, which is exemplary, it's still a lot of a solo journey. You're still alone while you're doing it and when you can't – even though I know that whatever I'd ask Robyn she'd do for me or my children or stuff like that, it's still a lonely experience.

Andrew Denton: Five weeks later, in early August, a text arrived from Ray: “The sooner we speak the better. Getting syringe driver tonight. We should round things off with one last talk so you can understand how indecent this disease is”. Unsure of what to expect, I rang him.

When I got through, Ray told me that a few hours earlier he'd been in a very bad way, delirious and distressed. Because he could no longer swallow, a nurse was called to connect him to a syringe driver that would supply him with medication.

Andrew Denton: So I was a bit alarmed at your text. I could, I wasn't quite sure how to read it but where were you at five hours ago?

Ray: Oh, I was struggling to talk and you know, struggling to get by. Had to have people lift me up to stand up and I could only walk about 10 metres and I'd fall back and, you know, so there was all – it's been a big mess, really.

Andrew Denton: When I last saw you, your body was degenerating pretty rapidly. Has that continued?

Ray: Yeah, I, I'm down to 44 kilos, so...

Andrew Denton: Whoa! Yeah.

Ray: It's, it's pretty thin on my frame.

Andrew Denton: Yeah.

Ray Godbold: So um, I yeah, I don't look good.

But the way that I've picked up over the last three hours, it's turned me round really. But I'm still, way out of the deep hole I was in. And even my kids, we've all had a tear session today.

Andrew Denton: Mm hmm.

Ray: Because we thought that, you know, it's 48 hours at the most, because I couldn't do anything for myself.

Andrew Denton: Despite his rapidly deteriorating condition, a few weeks earlier Ray and Robyn had somehow managed to get to Palm Cove. I asked how it had gone.

Ray: Yeah, well, Palm Cove was a little bit disappointing. It was great seeing our parents – parents! It was great seeing our friends.

Andrew Denton: [Laughing] That's the delirium again, isn't it?

Ray: It is the delirium. It was fantastic seeing them. But there was a weekend when all of Australia got a cold snap of weather. It was freezing and I had to watch everything I did and had to walk about slowly.

Andrew Denton: Oh! I just had this picture of you lying on a deck chair somewhere actually soaking up some rays.

Ray: Yeah, with a great big pair of white plaster across my nose.

Andrew Denton: Yeah, yeah.

Ray: I'll have to send that picture to you.

Andrew Denton: [Laughing]

Andrew Denton: At the airport, on his way to catch the plane to Palm Cove, Ray had a fall – one of many, this one so bad it nearly derailed their plans.

Ray: I went splat, straight onto my nose and my knees.

Andrew Denton: Did you break your nose?

Ray: Oh, yeah, I've got a little bow in it, yeah.

Andrew Denton: Oh.

Ray: I feel it's a little bit too late in life to get it straightened out.

Andrew Denton: Maybe.

Ray: It wasn't exactly, um, a romantic look.

Andrew Denton: A few minutes later, Robyn came on the line. Between the delirium and the constant danger of falls, Ray had become increasingly challenging to look after.

Andrew Denton: It sounds like it's been a pretty emotional day?

Robyn: Yeah, yeah, it's been a really big day, yeah.

Andrew Denton: And how are you coping?

Robyn: Yeah, no, I'm coping alright. I just feel like I'm in a bit of a parallel universe to some degrees. It's real but it's not real, you know?

Hang on I've just got to help Ray get out of bed. He just has trouble from sitting to standing.

Andrew Denton: Sure.

Robyn: Do you want me to help you up, or...?

Ray: [muffled] It's alright.

Robyn: No, he's alright. He'll just stay put where he is for a minute.

Andrew Denton: God I'm tense just listening to this, because this sense that Ray's been falling over so often is very disturbing.

Robyn: Yeah, yeah, it's been – did he tell you about the airport?

Andrew Denton: Yeah.

Robyn: Yeah. There's a good photo of him at the airport after they'd patched him up, with bandages all over his face. It's pretty funny.

Andrew Denton: I told her Ray was planning to send me the photo. I also wanted to know how the last 24 hours had affected their thinking.

Have you discussed the Nembutal at all or is that kind of out of the conversation now?

Robyn: Yeah, we have discussed it, quite a bit lately. And um, yeah, it's still there if he needs it.

Andrew Denton: Is that good to know?

Robyn: Yeah, yeah, it is. And probably, I mean – well when he got confused and had the chest infection and was quite unwell. I thought, “Well that window of opportunity has passed,” because he wouldn't be able to do it. And now his swallowing and his oral intake's not very good so I don't know even if he could keep it down.

But then, you know, it may be possible, maybe not, but he's just going to see what happens. It's interesting, though, because all these ideas that you have, coming up to this stage, you know, yeah, I don't know, it's just different when you're actually in it. You know, like with Ray getting confused – that wasn't something that I had considered. I'd considered his physical demise but not that mental side.

Andrew Denton: Yeah. No, I was going to say I just, I really – my thoughts are with you for the days ahead because they're not going to be easy days.

Robyn: No, no. It's not going to be easy at all. But we'll get through it I suppose. Everyone does.

Andrew Denton: When Ray came back on the line I asked what his thoughts were about the Nembutal.

Ray: Robyn and I have decided we're going to keep it here and we'll see how this clinical pathway goes, and if the pain or the vomiting or whatever got too severe, I would still be open to taking it, but if I can control the pain and the other symptoms on the palliative care pathway, I'll continue on that, as we can.

Andrew Denton: Knowing that the Nembutal's there, what does that mean for you?

Ray: Oh yeah, it's still a comfort, you know?

Andrew Denton: If you're having trouble swallowing, which is I believe part of the reason you got the syringe in, is that going to be an issue if you decide well maybe it's time for Nembutal.

Ray: Well possibly because I don't think you can go much lower than 44 kilograms, on my frame. But I've just got to go with what I feel is the right thing for me and I think that's a reasonable stance, you know?

Andrew Denton: Well that's the whole point isn't it? About choice.

Ray: Well yeah, it's all about choice. We don't know what's going to pan out in the end. I still could have something catastrophic happen to me.

Andrew Denton: Are you scared? Are you...

Ray: No, not scared. Like I said, I've got good children I can talk to, you know? I feel like I'm very well supported. I've come to the conclusion that it's just inevitable.

Andrew Denton: I'm going to go because I'm mindful that you probably need to just rest up, but I'm not sure when we'll talk again, but in case we don't, it's been really good talking with you and ah, my love to you.

Ray: Yeah, no worries, mate. Thank you. It's been fantastic talking to you as well.

I'll send the photo of me at Tullamarine airport, alright?.

Andrew Denton: [Laughs] OK. It was good talking to you.

Shortly after I hung up, the photo arrived. It shows Ray, sitting in a wheelchair, a jaunty hat for the tropics on his head, sticking plaster all over his nose and forehead, and a big smile on his face.

Two weeks later, Ray died. He was 59.

[BLUES SONG]

Andrew Denton: Four hundred people turned up to farewell Velvet Ray. The three kids spoke and some of Ray's beloved blues music filled the room.

A fortnight later, I sat down with the family one last time.

Andrew Denton: Robyn, as you got into those last couple of weeks what was the thinking about Nembutal?

Robyn: Um, well, he got quite acute delirium, which meant that he was quite confused. He came in and out of it, but um, yeah. And then, you know, we had quite lucid discussions and stuff, and he felt that if he was comfortable with palliative care, he was happy to take that approach. He wanted to die at home. He wanted to die in his bed. So we did discuss Nembutal. He said, "That's my backup plan, but I'll try and go with the system as it is". And I think probably because of the repercussions, because he wouldn't be here to have to deal with any flack.

Andrew Denton: What was he concerned about?

Robyn: Well, I think he was concerned about the legal ramifications and, looking back in hindsight, I just feel that when he was well enough to take the Nembutal he didn't want to, and I think Ray, as much as he, you know, came across as being prepared – he was prepared mentally, when it actually confronts you and you actually are dying, he didn't want to go.

So it's been interesting. It hasn't changed my view on having a choice at the end of life but it's made me realise it's so complex. It's a hard thing to end it by your own hand – to get that Nembutal out yourself, which is what he would've had to do, otherwise we're assisting him. It's hard. It's really hard to do, no matter how you've processed that thought intellectually; it's extremely hard.

Andrew Denton: As you said, there's nothing simple about this. There wouldn't be a more experienced person in these matters than Ray. But even for him, there was absolutely no way of knowing how things were going to unfold.

Robyn: Yeah. And things cascaded and, yeah, it sort of was out of his control.

He was quite disorientated and then, the day before he went to hospital, we sat down and we had to have the conversation with him. We all were there and said, "Do you realise that you're dying?" Like, "That it's you that's dying?"

Tara: Because he thought he just had a chest infection and he was going to get better, and he said that a few times. But then he said something and I was just like, "Do you know what's happening, Dad?" And he just said, "No".

I went and got Mum because I was like, I don't want to do this. And then we were like, "Do you remember?" And he was like, "Yeah. Oh yeah!"

Rory: But it was difficult to say that to him.

Andrew Denton: To tell him he was dying.

Rory: I found that moment really hard and I had to keep leaving the room, because to say, “You've got cancer; you're going to die. We're trying to make you comfortable”... And you were saying things like, “It's OK, it's OK to go to sleep, it's OK to let go”. That was really – the reality of that for me was really...

Robyn: You know how he used to talk about existential distress, well we did get to see a very classic demonstration of that. And at one stage – you know how he talked about not wanting to be cold, well he, in the end he couldn't keep his clothes on. And the poor kids one day were exposed to him. He pulled everything off, and his breathing – and we were just having trouble getting enough drugs into him, and he was wandering around the house and he had to – Rory said I was a ninja trying to get the drugs....

Rory: He was walking down the corridor and Mum was getting the syringe in and...

Tara: And I had a dressing gown trying to cover him up, and he's like, “No!”

Andrew Denton: Yeah. Geez, not a scenario you could ever have imagined happening in your lives.

Robyn: No, and the last little bit before he went to hospital was the most distressing thing I've ever seen in my life.

Ella: Awful.

Andrew Denton: Can you tell me about that?

Robyn: He woke up at five o'clock in the morning and he was really agitated, and he just kept trying to get up but he couldn't really walk that far.

He was so short of breath. It was just horrendous. Absolutely horrendous. And I was just giving him medication and the kids got up. And, you know poured so much, and I was giving him double, triple, and nothing seemed to work and that's when he asked for the Nembutal.

Tara: “Get the Nembutal! Get it! That brown bottle up there.” Oh it was awful!

Rory: Yeah, it was the moment for him.

Tara: Yeah, he was ready. He wanted to.

Andrew Denton: Was he – do you think he was lucid when he said, “Get the Nembutal”?

[ALL]: Yeah.

Tara: A hundred percent.

Rory: Because I had to explain to him that he wouldn't be able to drink it, and he understood.

Andrew Denton: Because he couldn't swallow?

Robyn: He just kept regurgitating any – he could get a mouthful of water down, but you have to kind of take it when you're in control, and that's why I think the law, that's why it brings it home about the laws. Because if we could've given him something intravenous or by some other form if it was legal, then we could've relieved that distress.

Andrew Denton: Yeah, even a syringe driver which he could control.

Robyn: Yeah. But if it's legal then, and you've expressed the wish and all the forms are done and whatever, hopefully someone else could administer it. Is that how it works in...?

Andrew Denton: Look yeah, that's how it works in Belgium and the Netherlands.

Robyn: Yeah, which would've been ideal for Ray. That would've been the time.

Ella: It was very stressful. Like we were all trying to comfort him, and it was – I had to walk out of the room at one point because it was so hard to see. It was awful! I will never forget the look on his face, ever.

Rory: He knew he was dying that morning but because he was so short of breath I think he was really distressed. He was like, I don't want to die in this way. I don't want to suffocate to death.

Robyn: I have seen a lot of people die, in my career and he was the most distressed of anyone I've ever seen.

Andrew Denton: He's like the living example of why there should be a law.

[ALL]: Yeah.

Robyn: In some ways it's solidified all our beliefs about why he was fighting.

Andrew Denton: In the end, having tried everything to help him, the decision was made to take Ray to hospital.

In an ideal world, in specialised palliative care, one of the suite of options they offer to somebody like Ray who is in his last hours is the option of a peaceful death.

Robyn: Yeah. In the end, he basically had terminal sedation, which is they just upped everything to max. He had the biggest dose of morphine they've seen at the hospital

Andrew Denton: How much better do you think it would've been if this was legal and it could've been openly discussed and you could've had your GP with you if need be, that it could've been something there'd be no questions about would there be police involved afterwards. How much difference would that have made to the conversation with all of you, do you think?

Robyn: Oh, much, so much easier. Yeah. We could've, yeah. Because I think that was a concern for him because he would, you know, he would've been gone and if there was any consequences of him taking the Nembutal, then the family had to deal with it and not him

Ella: I understand it a whole lot more now – what it means, why we should be talking about it and why we should be advocating for it.

I will always look back and think Dad always died with dignity, because I remember him in himself and not the way he died, although it will haunt me. But I absolutely understand the point of what it means to die with dignity and how every case is so different. It's not just a matter of saying that this is the law; it's just about having choice. It's not going to suit everybody. But there are certain circumstances with how people die that are quite awful and often it won't apply to a lot of people, but in circumstances like Dad's, it would've been so comforting for it to have been applied to him.

Robyn: I think the medical system intervenes, we intervene at every stage of life, constantly intervening. And it's bizarre how we can't do it. And in the end we gave Ray terminal sedation, you know. They just upped the morphine, and it was a dose of morphine really, in the middle of the night, that caused him to die.

Andrew Denton: Ray Godbold wanted to die at home, in a dignified manner that he could control and that would spare him and his family the worst of his dying. In the end, he got none of those things.

While the knowledge of having an illegal supply of Nembutal did provide him with comfort in his dying months, ultimately it wasn't enough.

Had Ray lived in Oregon or The Netherlands or Belgium, their laws for assisted dying would have meant he could have had the best that palliative care could offer, with the clear understanding that should the suffering become too much, he would then have had the option of dying peacefully and as he wanted.

Instead, because there was no law in Australia to protect him, he had to plan his own death in secret. And when his dying ran out of control, there was no-one that Ray and his family could legally turn to, to help him in his last wish.

Instead of being able to farewell his family, the only option offered to Ray was to die in a medically induced coma, the memories of his dying hours leaving those he loved with an indelible scar.

Doctors who oppose assisted dying in Australia like to reassure us that there's no need for it because everything can be taken care of by palliative care. But as Ray knew – and as his death tragically shows – that is not always true.

None of us know how our own death is going to be. All we know for sure is that it's our own. And because it's our own, what Ray sought – and many others like him – is a choice about how we face it, not to be told by others that we can only die in ways that satisfy them.

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

Andrew Denton: In the next episode of *Better Off Dead: FUD*. Fear, Uncertainty and Doubt – the three seeds sown by opponents of assisted dying that have been reaping them a rich harvest of political inaction for years. For the first time, we're going to pick apart those little

seeds of FUD and reveal the tactics still winning the hearts and minds of Australian politicians today.

[SONG 'FORTY EIGHT ANGELS' BY PAUL KELLY]

[CLOSING CREDITS]