

Episode 3 – The 80-year-old outlaw

[SUICIDE WARNING]

[PRAYER BELL CHIMES]

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

[ABC 774 radio ID]

Jon Faine: Steve from Point Lonsdale's on the line. Good morning, Steve.

Steve Guest: Morning, Jon.

Jon Faine: What can we do for you?

Andrew Denton: On a cold winter's morning in 2005, top-rating radio host Jon Faine took a call from a listener for which he was completely unprepared.

Steve Guest: I can't see any Christian compassion. I'm dying an awful death.

Jon Faine: You're what, sorry?

Steve Guest: I'm dying an awful death of cancer. I have cancer of the oesophagus, which means that I can't swallow. I'm as good as dead now, Jon. I've probably got less than a fortnight to live, at this stage. And for the past few months, I've had no quality of life whatsoever. I'm in pain 24 hours a day. I can't eat, I can't do anything, I'm as weak as a kitten. I can't even hang washing on the line, and I want my life to end. And that's all I ask. And these bastards who call themselves Christians, they won't let me have that death, Jon. And that's all I want now. I want a pill in the cupboard that I can reach for, and take it, and end this nightmare that I'm living at the moment.

Andrew Denton: As Melbourne listened to Steve Guest's desperate wish to die, one man stepped forward. His name was Doctor Rodney Syme, and he is Australia's oldest outlaw.

[OPENING CREDITS]

Andrew Denton: My name is Andrew Denton, and you're listening to *Better Off Dead*.

A quiet, leafy street in one of Melbourne's most exclusive suburbs - not where you expect to find a man who's been openly baiting the law for over a decade.

80-year-old Rodney Syme believes that patients who are suffering unbearably, and who are beyond treatment, should be able to ask their doctors for help to die. Even though it's illegal in Australia, for more than 20 years, he's been providing that help. According to Canadian anti-euthanasia campaigner, Alex Schadenberg, this makes him a threat to society.

Alex Schadenberg: I think it's a complete injustice that they have not brought Rodney Syme to justice, and the reasons are very simple. These people by being wild cowboys - they're the worst of the worst.

Andrew Denton: So how did a respectable, 80-year-old urologist come to be a law-breaking cowboy, the worst of the worst? It began 40 years ago with his patient Betty, who was dying of kidney cancer.

Rodney Syme: She had neuropathic pain due to nerves being irritated and compressed, and it's the worst possible pain. Effectively you need an anaesthetic to relieve it. So I used to visit her every day and see what could be improved, and I could hear her screams as I entered the hospital foyer. She was on the first floor. And it was agonising. I would come to visit her and sit in my car - I can remember it well - for 5 minutes, trying to summon up the strength to go and see her. That was bad enough for me. Imagine what it was like for her and her family!

Andrew Denton: Impotent in the face of Betty's pain, Rodney could have chosen to look away. But he chose differently.

Rodney Syme: I couldn't get it out of my mind. I just felt that was the most appalling thing that could happen to anybody, and I thought to myself if I'd been in that pain, I didn't have the slightest doubt that I would have ended my own life rather than go on like that. And of course I knew that that was possible for me. I was a doctor and I had access to medication, I had colleagues who I knew could help me if I needed help. So I thought, "What's ethical about me being able to end my own suffering but my patients have to go on?" And that really changed my whole life.

Andrew Denton: Three years later, Rodney was confronted by Len, a man with incurable bladder cancer, whose treatment was only prolonging his death.

Rodney Syme: And I made the urologist's response of saying, "Well, we'd better put you into hospital and make you more comfortable," and he looked me in the eye and said, "Isn't there something else we could do?"

Andrew Denton: Were you quite clear that was what he was asking?

Rodney Syme: I hadn't the faintest doubt. It couldn't have meant anything else.

Andrew Denton: Unable to ignore his conscience, this time, Rodney decided to act.

Rodney Syme: I wrote a prescription for sleeping tablets, the maximum quantity that was allowable, and I said to him, "If you go home and take these, you probably won't wake up". And I knew it was the question he was asking because the change in his face was dramatic - from somebody who was being crushed by his illness, his eyes lit up and a smile of thanks came across his face.

Andrew Denton: That night Len took the tablets. But they were not enough.

Rodney Syme: The naivety of it was that the medication I was prescribing for him was not adequate to do what he wanted. He did go into a deep sleep. His daughter came and found him. The police broke into the house, and he was brought back into hospital and he actually did die essentially without waking up, but it took about a week for that to happen. So it was a very naive, impractical outcome. It was clear to me that it was potentially dangerous for me to have done that. I hadn't thought about it. Anyway it led me to think more deeply about the whole matter.

Andrew Denton: Rodney started to read widely about assisted dying. He spoke out publicly in support of it. Other patients came to him, and he assisted in what limited ways he could. It wasn't until 18 years after his clumsy attempt to help Len that he was fully confronted by the magnitude of being asked to help someone die.

Andrew Denton: Can you tell me - when was the moment when you realised that you were outside the law and at risk of prosecution, and knowingly so?

Rodney Syme: I guess this happened with a woman who had multiple sclerosis. She was virtually completely paralysed. She had attempted to end her own life. This was before I met her.

Andrew Denton: Alice was in her fifties.

Rodney Syme: She was frightened to have another attempt, but eventually got in touch with me. And I visited her, and indicative of my fear at that time, I remember

well, I parked my car about 300 metres away from her house so it wouldn't be recognised that I was actually visiting her, and I crept up the street into her house hoping nobody would see me. We had a long talk, and she had no medications that she could take which would reliably end her life. I said to her she should have a chat with her doctor and see what he might be able to do. He was not helpful. I said, "You could find another doctor". She said, "No, there's no doctor who will come and visit me".

Andrew Denton: Rodney was unsure what to do.

Rodney Syme: Following that she sent me a letter which said how disappointed she was that I couldn't help her and was there anybody else that I could put her in touch with. It was clear that I had failed her, and I thought, "I can't just leave this woman in this dreadful condition". When I met her she was lying on a trolley, she couldn't move any limbs, she was catheterised; she was in a very bad state. And again my conscience kicked in and said, "Look, this woman is chastising me for cowardice," and it was. I wasn't prepared to stump up, and I thought, "No, I won't let that happen". I had to make a really serious decision as to whether I was going to assist this woman to die. I had never done it before.

Andrew Denton: Rodney researched medication that would end Alice's life. He then put her into hospital under his care until she died peacefully.

Andrew Denton: Assisting a suicide carries a maximum 5-year jail term in Victoria. But, to his surprise, Rodney found that the law didn't want to get involved.

Rodney Syme: Because I was publicly saying that I was helping people I thought well maybe the police will get a search warrant. That never happened. I was interviewed by the police on up to nine occasions and they were sympathetic and apologetic and just going through the motions, so I gradually formed the opinion that really the authorities were just trying to evade this issue.

Andrew Denton: With each new public statement, more and more people approached Rodney for help.

Rodney Syme: They had powerful arguments for needing advice and assistance. I found I couldn't deny them the respect of talking to them and in some cases helping them. That is an interesting point, because in many, many cases just talking to them was powerful therapy, and many of them didn't need anything more than that.

Andrew Denton: It was 22 years ago that Rodney helped Alice to die. And since then?

Rodney Syme: It would be over 100, I would say - more than that, more than that. I've got no notches on my belt or anything like that. You do what you have to do.

Andrew Denton: If you've helped roughly 100 people to die, how many people would have requested your help, do you imagine?

Rodney Syme: Well, I have counselled well over 1500 people - not all of those would be wanting to die.

Andrew Denton: I'm curious. How does Rodney decide who to help and who not? In the absence of any guidelines, what criteria does he use to turn someone down?

Rodney Syme: You do get a wide range of requests, and some of them are clearly based on overreaction to the circumstances that they are in. For example, I can remember a couple of people with cancer which was eminently treatable, but people's minds just sort of freeze. They say, "Cancer - I can't bear to go through that, I want to end my life". The help they need is to be advised to reconsider their situation and undergo treatment. There are people with no physical illness whatsoever but have clearly got psychological disturbance. And they have tremendous suffering. But I have never assisted anybody in that category, simply because I don't have the training to make that sort of decision. I have had people who have lost all their money, you know. They are suicidal in fact. They need good psychological counselling. They have got a situation which can recover with the right treatment, so I advise them to get psychological help and point them to a good person. But they are not difficult to detect.

Andrew Denton: The people coming to Rodney were in unbearable and untreatable pain, patients for whom their doctors could - or would - do no more. The more he helped, the more Rodney learnt that even the offer of help was powerful medicine in itself.

Rodney Syme: I've had patients who've been absolutely distraught about their circumstances. You give them medication, involve them in a careful discussion, give them support and their whole demeanour changes. You relieve that terrible anxiety and sense of having no control. You give them control and the pain diminishes.

Albert Leonzini: My name is Albert Gabriel Leonzini. And my age is 70. And what do I do? Nothing.

Sandra Morris: [Laughing]

Andrew Denton: Albert Leonzini lives with his partner Sandra Morris. Faced with a crushing illness he has turned to Rodney for help.

Albert Leonzini: I do nothing - because since I was diagnosed, six months ago, I haven't been able to do anything. And that's given me an excuse to be a bludger.

Sandra Morris: [Laughing]

Andrew Denton: Albert has a disease so ugly that, in Australia, it has its own nickname - "the bastard". It's motor neurone disease, and medical science currently has no way to cure it.

Albert Leonzini: Well it was very easy to research, very easy. Because basically it says, "We don't know where it comes from, we don't know what causes it, there is no cure, so go home and die". So you have to accept it. There's nothing you can do about it.

Andrew Denton: For those that don't know anything about this disease, can you describe on a day-to-day basis what it's like to live with?

Albert Leonzini: Well it's restrictive. Because I can't drive, I can't walk. And, you know, everything's been affected. So my life constitutes of lots of rest in bed, lots of rest - up to 20 hours a day. I get up for breakfast - two hours for that, and I get up for dinner - another two to three hours. So nearly 20 hours a day in bed.

So that's where I am. And it hasn't really killed me, in the sense that I don't sort of say, "Oh, what kind of a life is that?" I don't say that.

Andrew Denton: You still seem very full of life to me, notwithstanding the routine that you have to live. What are the joys in your life still?

Albert Leonzini: Sandra. She's my strength, she's my carer. She's everything.

Andrew Denton: Sandra and Albert have been together almost all their adult lives.

Sandra Morris: We didn't get married.

Albert Leonzini: Didn't get married.

Sandra Morris: No. We chose not to be married – well we just never...

Albert Leonzini: I didn't want to get married because I was waiting for the right woman.

Sandra Morris: [Laughing] That's 45 years he's been waiting.

Andrew Denton: So Sandra, you are – if I can put this romantically – you are a placeholder.

Sandra Morris: That's right! Absolutely. No, we, neither of us - it was just not important.

Andrew Denton: Albert had always believed in his right to control how he dies. But in Australia - because the law denies him that right - believing it, and knowing what to do, are different things. Then Sandra heard about Rodney Syme.

Sandra Morris: And so I rang up and made an appointment ...so he came here and he met Albert and me and chatted and put us at ease instantly about choices. And from that moment we had - I mean you can say how you felt, Albert – but *I* felt the most incredible relief, right?

Albert Leonzini: Rod's a great guy. He's a great guy. ...Because when you're told you're going to die the first thing you think about is the pain involved, right? And Rod made me feel very comfortable, because he said, you know, 'We know what to do, it's not going to be painful at all, you're going to be in charge. It's going to be your decision'.

Andrew Denton: So when the time is right he will supply you with Nembutal?

Albert Leonzini: Yeah.

Andrew Denton: And you will administer that yourself?

Albert Leonzini: He's even told me how to do it, which is just swallow it.

Andrew Denton: How will you know the time is right?

Albert Leonzini: That's a good question, Rod said that I'll know. You know when you become weaker and weaker, less and less energy, harder breathing, harder swallowing. Breathing and swallowing is the key.

Andrew Denton: Sandra, you're entirely comfortable with this?

Sandra Morris: No. No, I agree with it, but I'm not comfortable with it, right? On the one hand I think, well that's the way it should be, because that's what he would want - to be self determining. He's been self determining all his life. And at the most important decision in his life he's not going to be allowed to decide for himself? That doesn't make any sense, right? On the other hand, you know, as his partner to know that he could decide that and then I'd lose him, it's very scary.

Andrew Denton: Well when the time comes, Albert, will you share it with Sandra or will you do it quietly ...?

Albert Leonzini: No, no, no. Sandra will be in the middle of everything. She'll be in the middle of everything. Yeah, that's the deal.

Andrew Denton: There are those who believe that assisted suicide is not an act of bravery, it's an act of cowardice - that you're not valuing life as it was given to us. How do you feel about that?

Albert Leonzini: Well my my answer to that would be: who gave us life? Right? Is it - in my case, because I was born Jewish, my first question is: why did Moses have to climb Mount Sinai to speak to God and to get the Ten Commandments? Does God have a hearing problem?

Sandra Morris: [Laughing]

Albert Leonzini: And if he did, and he created the world, he would have known where Mount Everest is, right? He would have said, 'Sinai, yeah, but can you get to Everest? It's easier to hear, it's much easier to hear.'

Andrew Denton: [Laughing]

Albert Leonzini: So that was my first - when I was a very young child.

Sandra Morris: [Laughing]

Andrew Denton: Good questions.

Sandra Morris: So he's been irreverent all his life as well. You can tell, can't you?

Andrew Denton: I can. And when you do pass on, and you meet God, what are you going to say to him, Albert?

Albert Leonzini: Oh, I'm going to say I'm sorry.

Sandra Morris: [Laughing]

Andrew Denton: Albert is deeply grateful to Rodney for offering him control over the grim death that MND would otherwise bring. What surprises him is that Rodney doesn't want to hide what he's doing.

Albert Leonzini: Initially I thought that he might manage it in secret, so that we were all breaking the law but, you know, we could keep it secret. Then I found out that it's the opposite. He doesn't want to keep it secret.

Rodney Syme: Well the law is a blunderbuss. What it says in the Crimes Act is that it is a serious criminal offence to aid and abet suicide or to incite somebody to suicide. And for years and years and years that has been interpreted that if a doctor were to do what I do, that I am breaking the criminal law. What I have done is to help people to end their own lives. I've not ended anybody's life.

I want people to go on with their life as long as they possibly can, but if they reach a brick wall and there is nothing you can do to relieve their suffering and they are requesting, of sound mind and fully informed, they are requesting help to die, then I believe I have a duty to do that.

Andrew Denton: Rodney wants to provoke the law so that a new and more compassionate one can be written. One that allows people with unbearable and untreatable suffering to request assistance to die.

Rodney Syme: Opponents to change say, "Oh, we are making decisions about whether you will live or die". Rubbish! You are making the decision. If you come to me and say, "I have intense suffering and I want help to die," it is arrogant of me to say, "Well, no, you don't have enough suffering".

Andrew Denton: Suffering. For Rodney, this is the key.

Rodney Syme: It is not a particular illness, it is not how long they have got to live. It could be, for example, somebody with multiple sclerosis – a chronic paralytic disease which lasts for years and years, and people can spend any number of years in the end stages in terrible suffering. There can be people with – chronic rheumatoid arthritis is another very good example, whose almost every joint in their body is riddled with arthritis and pain. They may not have a particularly obvious point at which they are going to die, but their suffering can be intense. A person, for example,

who has had a profound stroke and is paralysed and speechless but can go on like that for years in intense suffering. Are these people to be excluded? I don't think that's fair. The critical point is suffering, intolerable suffering which is unrelievable.

Andrew Denton: Rodney wants to see a law written using safeguards similar to those that have successfully worked overseas. The first of these is that the person requesting help to die has to be mentally competent.

Rodney Syme: You need to establish that they are rational, that they are capable of making decisions, that they have carefully considered that decision, that they do in fact have circumstances which align with the concept of intolerable and irreversible suffering, that all of these things are given due consideration, and if all of those criteria are met, then you have to check those against a standard, and that is another doctor who is convinced of the same phenomena. And if either doctor considers that this person is actually depressed and it is affecting their thinking, then they should engage with a psychiatrist. And they could say, "Well, you will need to have treatment of this depression before we can make a decision".

Andrew Denton: Rodney is well aware that the most common concern raised about such laws is that vulnerable people - such as the elderly and the disabled, may feel coerced into seeking an end to their lives. But, in his experience, people like this are easily detected.

Rodney Syme: You know, as an experienced medical practitioner I am talking to people all the time. I am exploring all the facets of their complaints, and it's the easiest thing in the world to determine after 10 or 15 minutes of conversation what are the reasons that you are asking me for assistance and to suss out if there is an ambivalence or ... that somebody else is behind there giving a little push. And besides which, think about this: do you think I could persuade you to end your life if you didn't think that was a good idea? People cling to life.

Andrew Denton: For Rodney though, the ultimate safeguard, one that has been dramatically effective overseas, is that the decision about whether or not to end your suffering is entirely up to you. This is medication, in the form of a drink, that you, and only you, can choose to take.

Rodney Syme: I think the provision of oral medication is by far the most effective thing to do, because the actual provision of the medication gives the person control. If you're giving lethal injections, the doctor has control. I think that's the wrong way around. If you give a person control, they may or may not use it. That's their decision, and they will not use it unless they are absolutely convinced that they cannot go on any further.

Andrew Denton: The law that Rodney advocates is called Voluntary Assisted Dying. It says what it means. It's Voluntary. It is assisted by a doctor supplying medication. And it is dying. These words have been carefully chosen because, in this argument, words are bullets.

Catherine Foster: You cannot just put a nice word in front of an unpleasant one and change the meaning. What about assisted suicide, aid in dying, death with dignity – call it what you will, it is at its core an attempt to sugarcoat death and particularly suicide.

Andrew Denton: That's US litigation attorney, and anti-euthanasia campaigner, Catherine Foster. She knows that a word like 'suicide' carries a historically dark meaning. She, and others who oppose these laws, try to harness that darkness wherever they can. It is a tactic that rankles.

Rodney Syme: I get so annoyed when the word suicide is used in relation to somebody who has got unbearable suffering, terminal illness, wants to end their life not because they want to end their life but because they want to end their suffering. To me this is a totally different circumstance to what we usually see as suicide.

Jon Faine: You may have heard Steve from Point Lonsdale calling in last week. He called in on talkback, and told us a most remarkable tale. The tale continues...

Andrew Denton: A week after his call to Melbourne radio, a dying Steve Guest was invited into the studio. He told listeners that he had been helped in a way that had fundamentally changed the last days of his life.

Steve Guest: But I can tell you now that that anxiety that I referred to that derives from this uncertainty and that fear has now gone. Offers have been made to me. It has included, ah, offers of help with obtaining the drug that I believe I should be able to obtain under prescription from my general practitioner. It's now available to me basically at call. So that's one thing, that anxiety has gone.

Andrew Denton: Steve died eight days later, in the company of his two brothers, using the medication Rodney supplied him.

Andrew Denton: Rodney continues to demand a response from the law, admitting on national television in 2015 that he had given medication to help Steve Guest die.

Tony Jones, Q&A: Can I just put it to you like this - are you actually trying to provoke the police to prosecute you?

Rodney Syme: Yes, indeed.

Tony Jones: So you can actually have a test case?

Rodney Syme: Yes, indeed, because I would argue that I can produce and provide a person with medication which provides them with palliation, relieves the psychological and existential suffering which they have when they are facing a dreadful death and I believe that is a palliative act.

Andrew Denton: It is a rare man who risks his liberty on a point of principle. And if a court case were to happen?

Rodney Syme: I think I will win. I think I will win - A, because I have got a sound argument that what I have done, my intention is to relieve suffering. Secondly, I would be judged by my peers - I think they would support what I have done with Steve Guest, that I would not be found guilty. But even if they don't prosecute me, the fact that I am not being prosecuted, having broken what everybody would see was the interpretation of the law, and I am not prosecuted, what does it say about the law? The law is a bloody ass. I

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

Andrew Denton: If you'd like to hear how things turned out for Albert and Sandra head to the episode page at wheelercentre.com/betteroffdead.

In the next episode, we hear the extraordinary story of Tasmanian woman Cathy Pryor - who was sent to jail for the mercy killings of her grievously ill parents. And we look at the human cost to a country where there is no law for assisted dying - but where people are being assisted to die anyway.

Rodney Syme: On a very deep emotional level to me helping people ... come to a peaceful end is very rewarding ... as a physician, ... and sharing in their death is a very profound, deep experience, and you never forget it. You never forget it.

[CLOSING CREDITS]