

Episode 2 - How dare you want to end your life: Liz's story

[SUICIDE WARNING]

[Prayer bell chimes]

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

Liz Le Noble: It's my birthday tomorrow; I am 48.

▫Andrew Denton: Happy birthday!

Liz Le Noble: Thank you.

▫Andrew Denton: What do you get a woman who is losing everything?

Liz Le Noble: Who's got Nembutal! [Laughing] Who's got Nembutal. You know what? You give her humour. Thank you.

▫Andrew Denton: OK.

Liz Le Noble: Invaluable.

▫Andrew Denton: This is Liz. She's dying of cancer. Liz wants to have a choice about how she dies. But, in Australia, there is no law for assisted dying, so the only way she can have any say over her fate is to live – and die – outside the law.

What is it like to live in fear that your death may incriminate the ones you love? That the only solution is to die alone? Welcome to Liz's world.

[OPENING TITLES]

▫Andrew Denton: You're listening to *Better Off Dead*. My name is Andrew Denton. I live in Sydney, Australia, and I want to find out why, in my country, good people are being forced to die bad deaths - and why we can't have a law to help them instead.

How did Liz come into my life? My producer, Bronwen, had gone to one of Philip Nitschke, EXIT International workshops in Sydney to find some people who could explain to us why they were seeking help to die.

Bronwen was talking to an older man about pain - the group was made up almost entirely of over-70s retirees – when a glamorous businesswoman in her 40s, sitting in the front row, turned around and said ‘they can’t control your pain, let me tell you. I’ve been there’.

When I first met Liz she looked nothing like a woman who was dying. Corporate stylish, whip-smart, and full of energy, Liz looked every bit the business high-flyer she is. When I suggested she might, in fact, be a cancer charlatan she let out one of her trademark huge laughs. But Liz is no charlatan. Her cancer is very real. And very rare.

Liz Le Noble: One per cent of the world's diagnosis of cancer is neuroendocrine, and I had a 1% version of it. It is a neuroendocrine carcinoma. It is not just a cancer; it is a carcinoma.

▣**Andrew Denton:** In actual terms though, what does that mean?

Liz Le Noble: It means that it is a non-well defined cancer and they can't control it; they don't know how it behaves. but more than likely it was going to continue to behave badly.

▣**Andrew Denton:** You're even an over-achiever in cancer.

Liz Le Noble: [Laughing] I agree. I agree! I am here because I am an overachiever!

▣**Andrew Denton:** Liz was told there was no cure and that all treatment would be palliative. To keep her alive, they hit her with everything they had. They blasted her with chemicals. They took to her cancer with the knife.

Liz Le Noble: So the first one was a complete abdominal hysterectomy, everything - ovaries, cervix, everything; everything was gone.

▣**Andrew Denton:** The list of Liz's surgeries is dizzying.

Liz Le Noble: A section of small bowel, lots of my peritoneum, gallbladder, appendix, half my liver and little bits of chunks of the other half that he'd left. It was huge, it was huge.

▣**Andrew Denton:** Liz's terminal diagnosis was two years ago. Defying all predictions, not only is she still clinging determinedly to life, she's putting together a business start-up to supply cannabis resin for gravely ill people like her.

But Liz knows – and the doctors know – that treatment is forestalling the inevitable: A painful death of cancer. So being the go-to woman that she is, Liz has researched ways she could be helped to die. The best solution, she discovered, lay in Switzerland, where the Dignitas Clinic offers assistance to foreign nationals with a critical need. To apply, she needed the support of her specialist.

Liz Le Noble: So I said, "I've been researching into Dignitas. You may have heard of that". And he nodded. I said, "I need two doctors to sign off on this. Would you be one of them?" And he just sat there and he said, "No". And there was a big pregnant pause, at which time I felt like Alice after just drinking the "Drink me" drink. I was about *that big* sitting on the chair. That's when the real patient-doctor "I'm the doctor; you're the patient" level of feeling came into the room. I was figuratively biting my fingernails, going, "Alright, Liz, go on. Do it. Ask him. Ask him". "Could I just ask, Doctor, why you wouldn't do something like that?" "Because it means I would have failed at my job". It was just those words exactly. So I found that curious that it had nothing to do with me.

Andrew Denton: I'm thinking of a word that rhymes with curious - "furious". I would have felt furious that it was about him at that moment and not me.

Liz Le Noble: Alright.. You're on painkillers, you're in pain. You're scared. You've got cancer. You're going through chemo. You're still trying to understand what's going on. you're being told by doctors - that you don't have much longer. And here is a doctor and he invoked his God powers at that time. "Who are you? How dare you!" That's how I felt. I felt judged. Very judged.

Andrew Denton: And what was the judgement?

Liz Le Noble: The judgement was "You would actually consider ending your life?". Which is actually incorrect judgement. I am not considering ending my life. Cancer's doing that for me. I don't have the choice in that. I just don't want pain. And you being the palliative expert - can't control it, and yet you want me still to die experiencing it. And you judge me because I don't want to do that.

Andrew Denton: Liz knows all about pain because she is one of the unfortunate people for whom even the strongest drugs that palliative care can offer barely touched the sides. Ever wondered what it's like to be so doped up on pain relief that you can't even tell people it's not working?

Liz Le Noble: And be floating in a psychedelic-coloured cube where you can't speak because you have got locked jaw from the drugs, you know that you are writhing around on a plastic sheeted bed, your hands are like they're clenched and you can't talk. You can't talk, and you are completely vulnerable and at their mercy. And I was like that for days.

Andrew Denton: The image I get as you were describing that is that it was like you were locked in a scream.

Liz Le Noble: Yes! That's exactly right. That's how I felt. And the fear of that, the fear that you feel. Nothing takes that anxiety away. You still have it. So I think probably when you are in that dying stage, that is exactly what it's like.

Andrew Denton: I sense that fear just hearing you, and I don't know what I would be more frightened of - will this thing ever stop or am I going to die?

Liz Le Noble: Well even at that point you still don't want to die. ... But I remember thinking, "Surely in modern medicine, modern science, I can't believe I'm actually experiencing this".

Andrew Denton: Plan C was to try again, only this time from China.

Blocked by her specialist from applying to Dignitas, but still determined to have a choice about how she dies, Liz turned to Plan B. She joined euthanasia advocacy group EXIT International, bought a copy of *The Peaceful Pill Handbook* and, using that as a guide, ordered the lethal – and illegal – drug Nembutal, online, from Mexico.

It never arrived.

Along with my producer, Bronwen, I am at Liz's place the day the package arrives.

Liz Le Noble: Push and turn. So the lid has come off.

Andrew Denton: That's a lot! That looks like a lot.

Bronwen Reid: It does, doesn't it?

Liz Le Noble: Look how much is in here! We are holding a bottle that is...

Bronwen Reid: Is this your first sighting of it, Liz?

Liz Le Noble: Yes. Jesus Christ! Look, I have already got it on me. That is enough to make me go to sleep. I've just got a little bit on the tip of my finger. That just looks like, I don't know, what's that – sherbet we used to get in the '80s.

Bronwen Reid: Ah yeah, yeah yeah yeah.

Andrew Denton: Liz has asked us to come over because she needs to test the white powder to make sure it is pure enough to kill her. Not a task she wants to face alone.

Liz Le Noble: This is ridiculous that governments make me do that. This is really ridiculous. Seriously guys, come on! We should have a polly here.

Andrew Denton: For Liz there is an extra urgency. Two days earlier she admitted herself to hospital with severe vomiting.

Can you just quickly tell me about - I know you had more scans in hospital - what did they show?

Liz Le Noble: Well, I have got weeks to live. I just got the news this morning.

Andrew Denton: Faced with the prospect of her imminent death, Liz is terrified that the dying will run out of her control and has rung Melbourne doctor, Rodney Syme, for guidance. In defiance of the law, Rodney has assisted over 100 people with advanced incurable illness to die, most with Nembutal.

▣**Rodney Syme:** I would suggest you take 12 grams. It is an absolutely completely reliable dose. You could either mix it with something that will sweeten it or drink it and then follow it with a chaser of something sweet that you.

Liz Le Noble: Yeah, scotch chaser is what I was thinking.

Rodney Syme: Just use it to rinse your mouth and get rid of that bitter taste. OK?

Liz Le Noble: The other thing, Rodney, is because this is affecting my liver, and the reason I was hospitalised is I was uncontrollably, violently vomiting.

▣**Rodney Syme:** Well have you got anti-emetic?

Liz Le Noble: I do but the vomiting broke through the anti-emetic.

▣**Rodney Syme:** OK. You would want to preload yourself with whatever anti-emetic you've got that is working.

Liz Le Noble: Yes, and do I take that for a couple of days beforehand, Rodney?

▣**Rodney Syme:** Twelve hours would be sufficient.

Liz Le Noble: Right, OK. So It doesn't make you sick. That's important to know.

Andrew Denton: This is the end of Liz's life they are talking about. In a reasonable society, this wouldn't be happening as a clandestine conversation on the phone.

Rodney Syme: You can be absolutely confident that it will do what it should do and that you will die very peacefully.

Andrew Denton: As I listen in to Liz's questions, I am keenly aware that she has a deeper concern than whether or not the Nembutal will work.

Liz Le Noble: Can I ask, Rodney, your... [tearful] Sorry, just give me a minute.

Can I ask your opinion about people that you have been with when they have drunk this – you have been with people when they have drunk this, yes?

Rodney Syme: Yes, I have.

Liz Le Noble: Have they had their family with them?

Rodney Syme: Yes. People are very worried that if they have their family with them, that the family will be in some jeopardy. Now that is completely wrong for a number of reasons. The first one is that nobody knows whether they are with them or not at the time. Who would know?

Liz Le Noble: Well it is just that I talked to my son about this, because that is one of the things that you do, you talk to people that you love and you tell them about what your plans are, and I started thinking about the people that...and I almost feel sorry for them ... but in one way or another they are either going to be with me when I die peacefully or be with me in a hospice over days, weeks and months and...

Rodney Syme: When you die badly.

Liz Le Noble: And die badly, and that's more traumatic.

Rodney Syme: So what memory do you think they would have if you die badly, compared to that where you've [indistinct]

Liz Le Noble: Yeah OK, I have to just think of that.

Rodney Syme: we have to change the law, so that this can be done openly and without all this hoo-hah and secrecy and so forth. It shouldn't have to be. It should be something, an option, which people can take or not take depending on their circumstances and beliefs, and it should be just that you could take it, you could tell your doctor you're going to take it, he knows, he has provided it, and he can be there and he just writes a death certificate.

Liz Le Noble: That's right. Well thank you, Rodney. I'm going to go ahead and we'll test all this. Should we have any issues with it, can I phone you back, please?

Rodney Syme: Of course you can – any time.

▣ **Liz Le Noble:** And you would help me out?

Rodney Syme: Absolutely.

Liz Le Noble: Thank you very much, Rodney.

Rodney Syme: I wish you all the best. You are a very brave girl.

Andrew Denton: I found it hard to listen in to that call and hear the anguish in Liz's voice. As if it's not brutal enough that she is dying – and has to plan how to do it in secret – Liz has a 22-year-old son who is due to be married in 10 weeks. Where do you even begin with that conversation?

Andrew Denton: Does Callum know that you have obtained Nembutal?

Liz Le Noble: Nope.

Andrew Denton: Are you going to tell him?

Liz Le Noble: Oh he knows I've been – I've talked about it with him, yes, because that's one of the things.

Andrew Denton: Despite Rodney's assurances, Liz is still deeply afraid of what might happen to anyone who is with her when she dies. Nembutal is an illegal drug. Her nightmare is that her son might be charged with assisting a suicide.

Liz Le Noble: Callum's a big, you know, gorgeous-looking boy, gorgeous heart, strapping. Bluff and bluster, you know - "Oh, Mum, don't talk about that! I've seen you stare down death". Blah-blah-blah, and do all of that. "Thanks, honey, that's great. But no, really, we do have to talk about this. Me getting this is illegal but, pfft! So what? But you being with me when I take that is apparently illegal."

And that's when Callum stopped his bluff and bluster. You could feel the change in the atmosphere of our talking. And he's looking at me and he said, "So what? What are we supposed to do? We sit there and we're there with you while you drink it and then we lock

up and go home and sleep in bed knowing that you're dead in your bed and come back the next morning and go, "Oh, look at that. Mum's died," and phone the police? The way he... It was pretty much like that and at the end of it he had such big tears in his eyes that... It's dreadful and there's no answer to that. I don't know what the answer to that is. Am I being cruel to him by..? That would be cruel. I think that would be cruel. And I don't know how to handle that.

Andrew Denton: So here I am, standing in Liz's kitchen, on a brilliant, sunny, Sydney afternoon, watching as she and Bronwen carefully test the Nembutal to see if it will kill her. Using a kit Liz bought from Exit, a calculator, and scales borrowed from her hairdresser, the powder is measured, weighed, diluted, baked, then weighed again. The process – exhausting and exacting – takes six hours. An afternoon out of the life of a woman with maybe only weeks to live. Frankly, it seems cruel.

The only good news: The test is positive. The powder is pure. Now comes a much harder test – when to use it. I ask Liz if she knows.

▣**Liz Le Noble:** Only when I know - when the gate has closed and locked behind me and I am actively dying, that's when I will take it. What the nanny state country that we live in is making me do is take it probably a week or maybe a month earlier, if I am lucky to be able to work out when that is, than when I have to.

▣**Andrew Denton:** Because you have no professional help or guidance in this?

▣**Liz Le Noble:** No. Only me, only me, and I have to do my kitchen table medical degree determination of that. But it's the logistics now. We have done extraordinarily well. My stress has been relieved again significantly. We know what we have got, we have got the pure stuff. We know that.

Andrew Denton: Simply having the means to control her death has given Liz peace of mind. But three days later I get a call asking me to come around to her place. When I arrive she's with her brother Jason. They have spent the morning shopping for coffins.

Liz Le Noble: I have chosen a coffin. We have done all like hard stuff today.

▣**Andrew Denton:** What was it like to choose a coffin?

▣**Liz Le Noble:** Yeah, that was a bit strange, wasn't it?

Jason: Mmm.

Liz Le Noble: We went to the one at Bondi Junction there and it is just downstairs in a big cavernous...

Jason: In the garage.

Liz Le Noble: Garage, with the \$550, the \$950, the \$4000, right up to the \$90,000 ones.

Andrew Denton: I'm sorry to digress but does the \$90,000 one have a bar? What is it?

▫**Liz Le Noble:** I think it's the wood and the carving.

Jason: They didn't have those in stock at the moment.

Liz Le Noble: Yeah.

Andrew Denton: For \$90,000 I expect another trip up top. Do you mind if I ask what you chose?

▫**Liz Le Noble:** I chose the second from the bottom but it just is not important to us. What was more important is, you know, the feeling, the venue, you know.

Andrew Denton: It is deeply weird to be talking about coffin-shopping, and - not for the first time - I marvel at this strong woman who seems to have said, "OK, Death, if you're going to co-habit, these are the rules".

But then Liz tells me her news – the real reason she has asked me over. The reason Jason is here too.

Liz Le Noble: The Prof finally phoned me back this morning - this is after days - finally phoned me back, and you could tell in the tone of the voice, it was very different, and he said, "Well, Liz, the lesions are growing enormously fast again, as fast as, if not faster than when we first discovered it".

Andrew Denton: Liz has learnt that there's a real danger of her bowel being blocked by the growing cancer. That changes everything.

Do you know what that means?

▫**Liz Le Noble:** A feeding tube goes in, and hence my inability to drink anything.

Andrew Denton: Which means no Nembutal.

▫**Liz Le Noble:** No Nembutal. And an undignified death in pain.

▫**Andrew Denton:** I hear something I haven't heard in your voice previously, which is fear.

▫**Liz Le Noble:** Yeah. Yeah. I'm starting to get fearful. So far, Andrew, I'm not fearful of death, still. I don't want to die, obviously. I am fearful of that end road to death when you are actively dying, I'm fearful of that. I know they can't control my pain. I know, I have been there enough, I have been in hospital enough.

Andrew Denton: Despite her fear of hospital, Liz has decided to undergo two more 21-day cycles of chemotherapy. At best, this gives her a 50/50 chance of avoiding a bowel obstruction.

So - just doing the maths here - 42 days, does that get you to your son's wedding?

▫**Liz Le Noble:** No, it doesn't. And in 42 days if it is not working, it very easily will block.

▫**Andrew Denton:** And if it's not working, that blockage could happen at any time?

Liz Le Noble: That's what he said, so that's what alarmed me this morning.

Andrew Denton: Liz is now faced with the terrible calculus of dying. Does she try and hang on till her son's wedding and run the risk that she will suffer the death she fears? Does she say goodbye to everything she loves and take Nembutal? And, if she does, how can she do that without incriminating her family?

Liz Le Noble: I can't take it in hospital. So I'm going to have to exit hospital, and then where do I go? Do I have to go to a hotel?

Andrew Denton: As I listen to Liz and Jason talk it through, there is a rising sense of panic in the room.

Liz Le Noble: I was kind of strategising in my head well I would have all of my medical papers with me just laying very clearly out beside, I would probably even have a pack of sleeping pills there, prescription, with my name written on the front of it - strategising it down as much as I possibly can, and Jason, why are you smiling? Because...

Jason: I'm not smiling.

Liz Le Noble: You're not smiling but you're thinking that I'm giving this away, but I'm fucking trying to get a strategy together!

Jason: I agree, but I'm not sure that at this stage - we haven't got the strategy together. Once we have the strategy...

Liz Le Noble: All right, tell me then - what is the strategy?

Jason: Anyway, having tablets on the sideboard is not necessarily...

Liz Le Noble: A good one or a bad one, but it's one that we need to talk about, right?

Jason: Exactly. I agree.

Andrew Denton: And the tablets are there, you believe, as a mask for what has actually happened?

Liz Le Noble: Yeah, and meaning - I was strategising that it would be a full box, let's say of just something like Stilnox, so it is quite obvious that there is only one left in it. Talking that through as a decoy. But once I drink this, I have maybe 60 seconds - some people fall asleep mid sentence - 90 seconds maybe, and then I am asleep.

Andrew Denton: So you were thinking you are on your own when you drink this?

Liz Le Noble: Yes. Well, what do I do? Because there is CCTV in a hotel, isn't there, of someone slipping into a room and slipping out?

Andrew Denton: Again, that fear of what will happen if someone is with her when she dies. When Liz excuses herself to go to the bathroom, I asked Jason what he first thought when she told him about her plan to use Nembutal.

Jason: We have had some interesting discussions about it because I think it's a pretty extreme thing, but I've come around to the fact that I support her and I will do what I can.

Andrew Denton: You say you have come around. What was your first response?

Jason: You fight to the death, you don't give up in any way. I now see that that is not necessarily the smartest, it's not the bravest, it's not the most courageous thing, but if you look at all other options, and that is the option to go through, I'll support her.

Andrew Denton: It's terrible maths you have to do, and yet I have spoken with people who firmly believe that Elizabeth's choice is an indication that she does not value her own life.

Jason: Ah yeah, I would say that that is patently bullshit. It is not a case of valuing life; it is a case of valuing the beauty of life. Life without quality is not life at all. It is a very simple thing.. Elizabeth is a real fighter. She has been a fighter in business, she's been a fighter in life. I'm proud of her. I'm proud of what she's doing. What I wouldn't want is people to go too soon, to take an early option, but it's a fine line between an early option or leaving it one week too late.

Andrew Denton: For Jason, like Liz, there remains a fear about what his involvement might mean.

Jason: I have a wife, I have a family. I support her. What level do I go to, to be able to give her full support without - I'm not going to go very well in jail. So I don't know at this stage where the line is that I cross. If I was comfortable in my own head as to where we stand, that would be a different matter. But that's what I'm saying, there's no real book that you go to that gives you the idea of, say, if you inject them, you are guilty, if you watch them drink three bottles of vodka and pass into a coma and die, you are not guilty, because you didn't do anything to stop it. If they take Nembutal and you didn't stop them taking it, are you as not guilty as you were not guilty with the three bottles of vodka? That's the blurred line that nobody knows.

I don't think anybody should die on their own. They should be surrounded by the people who love her - love them.

Andrew Denton: When Liz rejoins us, something has shifted in her. Her anxiety has given way to anger.

Liz Le Noble: Do you know what, guys? I think I just made another decision. I think what I have just done is I have crossed the threshold of asking too much, and whenever I started this journey the thing I was angriest about was that I would have to drink it and be alone. But I should have just shut my fucken' mouth and just gone, "I'll do it," and I'll just do it on my own and I'll curse the - make a few voodoo dolls of bloody - some politicians. Nup, I'll just have to do it on my own.

Andrew Denton: It's a terrible thing that's being demanded of this dying woman - and her family. But it's what happens when there is no law to help her. It's probable that no charges will be laid against Callum or Jason for being with her when she dies using an illegal drug. But Liz can't be sure - and why should she even have to ask the question?

Why should anyone be forced to die this way? I think back to when we first met and I asked Liz, in a perfect world, how her death would be.

Liz Le Noble: So if I was to have it in an ideal world, way down the track, I'm hoping, I can see myself laying in my bed with my son and my daughter in law, my brother- and sister-in-law just around me, maybe have a glass of Moet. And not prolong it. I don't want to have a meal or anything like that. It's just, like, got to do something and here we go - "I love you and goodbye!".

[Tearful] I imagine holding Callum's hand. I don't think, you know... I imagine holding Callum's hand and thinking about his birth at my death. That's it. I'd like it to be peaceful and I'd like it to be without the anxiety of fear of what's going to happen to these people that are with me now.

Andrew Denton: Liz made it to Callum's wedding, where, in her own words, "This ex-Logan chick rocked it right". Having fought fiercely against her disease for years, Liz died nearly four months later while under sedation in palliative care.

Liz was just one of a growing number of Australians illegally importing Nembutal. If you'd like to know more, head to the episode page at wheelercentre.com/betteroffdead.

Next episode, we're going to meet the man who Liz turned to in her hour of need, Australia's oldest outlaw, Dr Rodney Syme. For the last 20 years he has been publicly assisting people to die and challenging the law to do something about it. Why would a respectable 80-year-old surgeon run the risk of jail? And why does the law not stop him?

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