Better Off Dead

Transcript for season 2, episode 6: The Locked Box

DISCLAIMER: This program is not about suicide. If you, or someone you know, needs immediate assistance with suicidal ideation or depression, please contact your local 24/7 crisis support service. If you're in Australia, try Lifeline on 13 11 14, Kids Helpline on 1800 55 1800, or the other support services listed on our website at wheeler centre.com/betteroffdead.

For legal reasons, the words of Parliamentarians spoken in this episode are being performed by actors.

[PRAYER BELL CHIMES]

Ethereal female voice: Death is the last intimate thing we do.

Kristin Cornell: When he took it, he took a couple of sips and he put it down and goes, 'Oh, this shit'll kill you.'

Andrew: How do you make a medication designed for only one purpose: to end a person's life?

Michael Dooley: Look, I've tasted it. Everyone in our team has to taste it.

Andrew: Whoa, whoa, whoa, whoa! What do you mean, 'You've tasted it'?

Michael Dooley: Pharmacists, when you make mixtures and things, reality is, you need to taste them.

Andrew: What is it like to hand someone that medication, having told them it will kill them?

Michael Dooley: Saying that the first time to someone sitting two feet in front of you is probably the hardest part.

Andrew: And how does it feel to drive off, leaving that lethal medication behind?

Michael Dooley: We find leaving very difficult, because you have to say goodbye and there's no easy way. It's not a normal goodbye.

Andrew: Meet the pharmacists: the final step and final safeguard in Victoria's Voluntary Assisted Dying law. I'm Andrew Denton. You're listening to Better Off Dead.

[OPENING TITLES. VOICES OVERLAPPING]

Male MP: Minister, I refer to the Voluntary Assisted Dying substance, and I must commend whomever came up with that name. I would like to meet them one day because I think they have got a great future in 'Euphemisms R Us.'

Andrew: In the parliamentary debate about Voluntary Assisted Dying, lots of questions were raised about the medication to be used to end a person's life:

Female MP: Minister, can I just confirm that any of hundreds of poisons on the schedules can be combined to create this substance…

Andrew: The locked box it would come in:

Female MP: Is it the type of locked box they use at Chemist Warehouse from the dispensary that is just a flimsy plastic box?

Andrew: The medication's effectiveness:

Female MP: No-one knows what that lethal cocktail is comprised of, but there are very well documented side effects or delays in dying or distress in the person after they've had the cocktail.

Andrew: A person's state of mind when holding the medication in their hands:

Male MP: If I was in that situation, I would probably think about it every hour. 'Will I take it now? Will I take it tomorrow? Will I take it after I've watched my favourite TV show?'

Andrew: The state of mind of the family:

Male MP: Sometimes the relatives might be wanting to encourage the person to take their medicine – or take their poison, I should say.

Andrew: What might happen if the medication had to be picked up at a chemist:

Female MP: I am concerned for other customers who may overhear this and the effect that it might have on them, knowing that the chemist is dispensing a substance that will kill the person who is purchasing it.

Andrew: And, generally, whether this was a good idea at all.

Male MP: I think about giving loved ones tablets to take home, to take whenever they feel like they've had a bad day. Are we doing the right thing?

Andrew: Meet the man whose job it was to answer many of those questions: Professor Michael Dooley.

Michael Dooley: I'm the Director of Pharmacy for the Statewide Voluntary Assisted Dying Pharmacy Service.

Andrew: When you hear the word ‘pharmacist,’ you could flash to comedian Jerry Seinfeld’s description of ‘a guy standing on a platform two-and-a-half feet higher than everybody else, whose job is mostly to take pills from a big bottle and put them in a little bottle.’ Michael Dooley is not that guy.

Michael Dooley: So, my background’s oncology. I then worked as a pharmacist in oncology, so primarily in chemotherapy and treatment of patients. And then I went to the Peter McCallum, the Cancer Centre in Melbourne and worked there and became Director of Pharmacy there, and more recently, over to the Alfred.

Andrew: Michael loves the good that medical science can do.

Michael Dooley: I think the real exciting bit is when you see new medicines, when you actually see it making a difference to patients.

Andrew: But he’s been doing it long enough to know that medicine has its limits.

Michael Dooley: The prognosis for most cancers is still dire. There are some where it's improved, but there's many times that we can prolong life but prolonging it isn't always very tolerable. We’re always going to have conditions where… where patients are suffering towards the end of their lives, irrespective of the treatments we have.

Andrew: Michael was not part of the Voluntary Assisted Dying debate.

Michael Dooley: Literally the first time I read the legislation in detail was when I got asked, ‘Would I help turn it into the practicalities of it.’

Andrew: The law, as written, did not specify what the ‘Voluntary Assisted Dying substance’ would be – only that there would be one. It didn’t describe the locked box the substance would come in, and it was silent on how the substance was to be dispensed to the people who needed it. What it did say was that, once it was passed, there would be an 18-month pause so that the systems and training required by the law could be put in place.

Michael Dooley: My role was to go, ‘Alright, this is what's being put in place, then what I have to do is, is how do I make this safe? And how do I make it of highest quality so the patients, their families, during very difficult circumstances, a lot of those worrying things are taken out of the conversation.’

Andrew: Michael and his team had three core operating principles.

Michael Dooley: Making it simple, make sure it was supplied in a way that didn't result in patients being under any pressure to take it, but the main one was that it had to work, and it had to not cause suffering. So, the first thing I did was go and see what other people have done before you and take the best of what they were able to do, and then apply it into Victoria.

Andrew: To meet this challenge, Michael had several places to turn. Europe, North America, and Canada had euthanasia and assisted dying laws, some of them stretching back 20 years.

Michael Dooley Through a little bit of work over a few months, and having a few conversations with the right people, I was able to source the most suitable medication. And I think that took a lot of the potential concerns that people had off the table.

Andrew: The next challenge was that locked box.

Michael Dooley: We sourced a locked box because the legislation said, 'There needs to be a locked box.' We give the key to the patient. The patient can then give that key to whoever they like. It's the patient's property once we give it to them.

Andrew: Michael makes it sound simple. It's not. Questions about the locked box had continued long after the parliamentary debate had ended.

Michael Dooley: I used to get asked all the questions. 'Where's the key go? Does the key have to go into a locked box?'

Andrew: In many ways, the locked box was a symbol of politicians' fears about making something lethal, legal. To a pharmacist's mind, this didn't make a lot of sense.

Michael Dooley: This isn't radioactive, it's not Ebola. This is a medication that's incredibly unpalatable that's in a locked box. There's a lot of medications in people's cupboards at home that you get on the PBS, in a packet of 60 or a packet of 30, that, if you take that whole packet, will result in you dying. So, it's interesting that people get very concerned about this particular medication. I think some of those discussions are not really rational when you actually think about it.

Andrew: Still, people obsessed about it.

Michael Dooley: Everyone wanted to have a photo of the locked box, where I was more, 'Hold on, we've got to make sure we're using the right words.' You know, the patient doesn't care about the locked box. They've got bigger things to think about.

Andrew: Michael had bigger things to think about, too.

Michael Dooley: I made the decision that I didn't want the medication to have an expiry. I was acutely wanting to make sure there was no pressure on patients that they had to use it.

Andrew: Michael and his team also decided the safest way to distribute it was from just one place.

Michael Dooley: Very early on, we decided that it was really important that there was a sort of centralised approach. This wasn't a type of scenario where you could just go to any pharmacy or go to any GP and get a prescription. This is very different circumstances. It was really important for patients and their families to make sure you really had the ability to

deliver a quality service. So, we decided to have a Statewide Victorian Pharmacy Service. It is very different to just doing a prescription. The service is very different in how it supports medical staff and nursing staff, and how we have to go into patients' homes and have conversations with them and assess patients to do all the things we do. It isn't something that could just be done all over the place by different people.

Andrew: But there was one problem to which the Statewide Pharmacy team had no obvious answer: the taste. Here's Colin's sister Deb, describing her cancer-stricken brother's reaction to the medication.

Deb: He said, 'Oh, my God, that is bitter. It's taking my breath away.'

Andrew: Kristen Cornell's dad, Allan, in the end stages of Motor Neurone Disease, put it even more dramatically.

Kristin Cornell: He took a couple of sips, and he put it down and he goes, 'Oh, this shit'll kill you.'

Andrew: Can you confirm that the taste of the medication sits somewhere between 'absolutely shithouse' and 'completely shithouse'?

Michael Dooley: Um, yeah. One of the patients called it cow shit. Look I've tasted it, everyone in our team has to taste it.

Andrew: Whoa, whoa, whoa, whoa! What do you mean, 'You've tasted it'?

Michael Dooley: Well, you have to. Pharmacists, when you make mixtures and things, reality is, you need to taste them.

Andrew: How do you taste this, though, without dying?

Michael Dooley" Well, you only taste a little bit, Andrew. You have to do it. You have to taste it.

Andrew: What does it taste like?

Michael Dooley: Whatever you think's bitter, double it. Triple it. It's incredibly bitter.

Andrew: Michael and his team tried different ways to make the medication less repulsive to drink.

Michael Dooley: We tried putting it in whiskey, and we tried putting it in stuff to see whether anything made it any better.

Andrew: Other solutions were tried and discarded as impractical.

Michael Dooley: We tossed and turned about, ‘What are the options here?’ You can put things in capsules, but then people would have to take 40 capsules. Did you make it in a bigger volume, then people might not be able to swallow it?

Andrew: In the end, there was only one logical answer.

Michael Dooley: So, the original protocol had a significant volume, like half a glass, and we reduced that to a smaller amount. So, it was easier to take.

Andrew: For all their skills, it was the best Michael and his team could do.

Michael Dooley: There's no way we can really improve it. So, we get patients to know that once they start taking it, it's going to taste horrible, so just get it down as quick as you can. And we get them to tell us what their favourite drinks are. And while we sit there, we work out what they're going to chase it down with.

[PENSIVE MUSIC]

Andrew: The Statewide Pharmacy Service goes wherever people need them to be.

Michael Dooley: There's nursing homes and hospitals. But the majority is at home.

Andrew: The team’s arrival is the last step of a long and precise process. The man or woman – let’s call them Jo – will have had to undergo two independent examinations by two different doctors. Jo will have had to make three requests – two verbal, one written and witnessed – at least ten days apart. Jo will have had to prove mental competency and that their request is voluntary. Only once all the steps have been completed can a permit be issued and a prescription for the lethal medication written. And then it’s up to Jo to decide what happens next.

Michael Dooley: We only get involved when the patient or their carer contacts us, because we do not want to be in a situation where we feel that we're ringing the patient going, ‘Hey, your doctor's written script. Do you want us to come and give it to you?’ We don't want to, in any way, feel that we are putting pressure on them, so they contact us, and then we work out a time to go and see them, wherever they are in Victoria.

[GENTLE MUSIC]

Newsreader: 21 days ago, Kerrie Robertson died peacefully in a Bendigo nursing home. She made Australian medical history as the first person to utilise Victoria’s new Voluntary Assisted Dying law.

Andrew: When Kerrie Robertson ended her four-year fight with metastatic breast cancer in July 2019, her daughters Jacqui and Nicole described her journey on Melbourne radio.

Jacqui: So, the actual delivery of the medication, it's hand-delivered by the Statewide Pharmacy. So, it's not posted, it can't accidentally be administered or put in the hands of the wrong person.

Jon: So, after you filled in all the forms, you've seen all the doctors, everything has been attended to, an actual real, live pharmacist, a specially selected pharmacist, physically presents, one-to-one, 'Here is the medication' – is that how it works?

Jacqui: So, there's two pharmacists that come with that kit

Andrew: One of those pharmacists was Michael Dooley. There was nothing in the pharmacist's manual to tell him what would happen next.

Michael Dooley: Yeah, there was apprehension. We weren't sure how those conversations would go. We thought one of the things that we would see would be open conflict. We thought there may be arguments and discussions and, 'Don't do it,' and, 'Why are you doing it?' We haven't seen that. We've seen that their families, even though they may not – they don't want to lose their father or their son – will still be brave to support them in their decision. And that's really surprised us.

Andrew: Michael's apprehension quickly turned to appreciation.

Michael Dooley: We were amazed from day one how well we were received by the families, how their door was open, and their lives were opened up.

Andrew: No matter whose home they're in, the first thing the pharmacists do is offer to leave.

Michael Dooley: We tell them that we haven't got the medications with us. We do not bring the medications into the house. They have to ask us, and then we say to them, reiterate it a number of times in a number of different ways, 'Just because we're giving you these medications, you are under no obligation to take them. If you want us to leave them, we'll leave them with you, and you have to ask us to leave them with you, but at any stage that you don't want the medications to be here, you call us and we'll come and get them. We don't mind if you call us tomorrow, we don't mind if you call us the next day.'

Andrew: Every family is different. Sometimes only two people greet Michael, sometimes 15. Very occasionally, there's only one. Once invited into the house, a sensitive conversation begins.

Michael Dooley: We basically start the conversation with, 'Well, we're here to assess your cognancy and to show you how to use the medications and make sure you could use them if you want to. And we'll stay until we answer all the questions you have. And if you have more questions after we're gone, then we come back, or you call us.'

Andrew: People do have questions, of many kinds. Some are about the medication: what to expect once it's been drunk, even where best to drink it. Some questions, though, are harder.

Michael Dooley: We get lots of questions about whether we think they're doing the right thing.

Andrew: How do you respond to a question like that?

Michael Dooley: The way I would approach it – and I've been asked that question a lot – they're making a choice during a really difficult time. We're here to help them, as safe as we can be, in providing care for that decision they've made. And we say, 'We fully understand why you're here and why we're here to help you.'

Andrew: The reason why someone needs Michael is, usually, painfully obvious.

Michael Dooley: One of the things that strikes us the most is we check people's ID, and you see the photo on the driver's licence versus the person in front of you. And you see that amazing difference that's occurred over, sometimes, not a long period of time. And, and I think people don't always have the appreciation of how much patients can suffer, not only through their symptoms, but through their loss of quality of life.

Andrew: The pharmacists' average visit is two hours. They have their questions, too. Here's Jean Caliste, whose son, Robbie, was dying of Motor Neurone Disease.

Jean Caliste: The pharmacist, we actually had to give him a lot of information about ourselves. There was a lot of questions, whether there were people with psychological problems, whether there was firearms in the place or anything like that.

Andrew: A person applying for Voluntary Assisted Dying must be both mentally competent and free from coercion. Many MPs argue the impossibility of ever accurately assessing such things; that coercion can be invisible; that illness can impair a person's judgement. Michael, as the last safeguard, is checking for both, and knows what he's seen.

Michael Dooley: We haven't seen any aspects of coercion at all. They're at the end of a long journey and they're steely-eyed determined that they've got a choice and they know exactly what they're doing. And it just cements in your mind the intolerable suffering that they've been enduring, to be able to self-administer a medication to do that.

Andrew: And mental competency?

Michael Dooley: You have to assess whether they understand the information and whether they're able to retain it, and then make a balanced decision about that information, and then communicate it to us.

Nicole Robertson: They were so compassionate and lovely, and were consistently saying to Mum, you know, 'Kerrie, do you understand? Do you understand what we're saying?' And she was like, 'Yes, yes, I do. Yes, I understand.'

Andrew: That was Nicole Robertson, who watched the pharmacists with her mum, Kerrie. Katie Harley's dad, Phil, was also dying of metastatic cancer. He was more direct in his response.

Katie Harley: The pharmacist rocked up on the doorstep and he was a lovely bloke, and he had to say again before he would release the meds, 'Do you understand what these meds are capable of?' I think Dad sort of snapped at him and said, 'Of course I bloody do.'

Andrew: The ravages of disease can make giving consent especially challenging for a person seeking Michael's help.

Michael Dooley: We've seen lots of different patients with lots of different diseases, who can't see, who can't talk, who are paralysed, who are communicating by, you know, various technology. They're worried that when we get there, that they won't be able to communicate to us their consent, and they worry that they won't be able to pass the test that we're doing. And sometimes you got to get really close to hear what they have to say. And sometimes it takes a little bit of time, but we've been amazed in those circumstances, how well and clearly they've been able to demonstrate their consent

Andrew: Even at this late hour, there are times when Michael has to say 'no.'

Michael Dooley: There may be a difference between the time that we see them and the time that the doctors have seen them. We work very closely with the medical staff, but there's been a small number where they haven't been able to demonstrate they're able to take it and those instances, we've had to make a difficult decision to say 'no.'

Andrew: Difficult to imagine how hard it must be to give them that news.

Michael Dooley: That's one of the reasons we go in in twos: not being by yourself to make those judgement calls. But it's important that if they were unable to take it, or they were unable to absorb it, then giving them a medication such as this wouldn't be good for them. And so, we're making the decision that's in the best interest of the patient. They understand why we're asking these questions, and we make sure that we do that in a way that they understand the decisions that are getting made and why.

Andrew: Hard though telling someone 'no' is, it's not what Michael finds hardest.

Michael Dooley: The hardest thing that we've found, all of us, was telling the patient that when you take this medication it's going to result in your death. And we actually, we workshopped what we would say, because you have to be absolutely direct. There's no ambiguity here. 'This medication will result in you dying.' And I think it was, for all of us, saying that the first time to someone sitting two feet in front of you is probably the hardest part, I think.

[SAD MUSIC]

Andrew: The next step is to enlist the help of the contact person, usually a family member or someone very close to the person who is dying. Their legal duty is to return any unused medication to the Department of Health. Often, they are also the ones who prepare the medication to be drunk.

Michael Dooley: We have to make sure that someone is able to prepare the medication. And we've done this lots of times, and we've held hands and people are nervous, and we stay until they're confident that they've been able to show us and they're confident they can do it. And if that requires them to do it again, if that requires us to go back again, that's what we do.

Andrew: For Kerrie Robertson's daughters, Jacqui and Nicole, the care taken by the pharmacists was hugely reassuring, as they explained to ABC Radio's Jon Faine.

Nicole: They walked us through, step-by-step, making sure Mum was well aware at every stage exactly what happens with the medication. We did a mock mixing of the medication.

Jacqui: They bring a dummy kit with them.

Nicole: To practice, to make sure that there is no room for error.

Jon: And at every stage could your mother have said, 'Okay, I've changed my mind'?

Jacqui: Everyone was very clear that even if she was dispensed the medication, she was under no obligation to take that medication at any time. It was completely up to her.

Jon: Right through to the point where it's already mixed and it's there.

Jacqui: Absolutely.

Jon: And does she pick it up to drink?

Jacqui and Nicole: Yes.

Jacqui: And even if it had been mixed, and she changed her mind, they were very clear that if that happens, and she changes her mind, but she would like another kit, they can dispense another kit. So, at no point in time is she obligated to take that.

Nicole: There were also very strict instructions with what to do with the medication if, you know, there was a point where it was mixed and not used, or if it wasn't used at all.

Jon: So, everything's been thought through?

Jacqui: So thought through.

Andrew: At the end of all the checks, Michael often senses a shift in the room.

Michael Dooley: You can actually see the patient's anxiety reduce in front of your eyes. You see the family's anxiety go up. The patient is more relaxed because they understand that it is going to be okay. And the family's anxiety goes up because they're understanding that they're going to be losing their loved one.

Andrew: Emotions are high for everybody.

Michael Dooley: You can feel the family, you know, there's tears around you and sometimes people will leave a room when conversations are on because it's just too much for them. We've all been in circumstances where we've sort of had to eyeball the other pharmacist and go, 'Can you take over for a few minutes?' And families get it. They know we're human, and they… we tell them when we get there, 'Look, we've seen patients before but none of this is routine.'

Andrew: It's not routine for doctors either, some of whom are called on to inject patients with a lethal medication if they can no longer swallow.

Michael Dooley: I've been involved in a number of the practitioner-administered cases, seeing the patient immediately before and working with the medical staff and the nursing staff about what to do, and I've sat in rooms many times with medical doctors nervous and shaking and teary. And we're all human.

Andrew: And then, for Michael, comes perhaps the greatest challenge.

Michael Dooley: We find leaving very, very difficult, because you have to say goodbye. And we've all talked about how we do it, and there's no way to do it because all the interactions are very different. And we've had patients who are taking it immediately we leave, and we know that. You know, as soon as you say goodbye, things are going to start. What's interesting, though, is the families are aware of that too. There's some sort of humane interaction that happens. Often, it's just a look or they'll, they'll put a hand on our shoulder or give us a hug. They know we're human. And they see us being human too. Because, you know, we're sitting down on the bed or you're sitting down on the ground with them, or you're – the wife is upset, and you got to console her and all of those things. It's a human interaction. It's not a passing, fleeting thing. It's usually, it's done where they are, we're going into their homes. And there's no easy way, and we all have our own little way of doing it. But that's very difficult. You can't say, 'Oh, you know…' It's not a normal goodbye.

[SAD MUSIC]

Andrew: Kerrie Robertson endured years of every possible treatment while cancer took her apart. The medication Michael left her offered gifts no Victorian had previously been allowed: the gift of release and the gift of choice. Here's her daughters describing what that meant.

Jon: So, there you are, you're at the bedside.

Nicole: Yeah.

Jon: What happened?

Nicole: Well, Mum was really lucky because she was able to plan that day. We had made a playlist with all of her favourite music on it. She…

Jon: Any arguments about what it was going to be?

Nicole: Not at all. Not at all. She was a very big Bowie fan, so it had to be Bowie.

[JON CHUCKLES]

Jon: Would you regard it with hindsight now? It's a couple of weeks? Was it a good death?

Jacqui and Nicole: It was perfect.

Jacqui: Perfect.

[PEACEFUL MUSIC]

Andrew: Even after they drive away, the work for Michael and his team continues.

Michael Dooley: I think the most important thing that we do is, we do it in twos, and you have a car trip home. Sometimes that might be a four-hour trip. You talk about the case. We have a debrief afterwards with the team, and we all write a journal, post cases, as part of the process, and we all remember little things. I remember a son rubbing a dad's back as we're going through the process. And we debrief with the medical staff as well about how it went. Often there'll be phone calls before and after, and we thank the medical staff for their involvement, because we know that it's a difficult thing for them to get involved in.

Andrew: Less than a dozen people make up the Statewide Pharmacy team, playing a key role in a much larger web of healthcare professionals.

Michael Dooley: I've got a wonderful team with fantastic individuals. And the medical staff and the nursing staff and the navigators, and the Voluntary Assisted Dying coordinators at various hospitals are fantastic. So, there is a real collegial approach that's made it a lot easier.

Andrew: I ask Michael, ‘Of the 124 deaths recorded in the law’s first year, from a pharmacist’s point of view, how many have proved problematic?’

Michael Dooley: Of all the patients that we've treated to date, there hasn't been any that have taken the medication, that it hasn't resulted with them passing away. And we haven't

had any, what we would classify major complications. And I think that's a reflection of a lot of the hard work and the safeguards that have been put in place.

Andrew: That doesn't mean the process is without risk.

Michael Dooley: When patients are taking it themselves, in the privacy of their own home, anything can happen. That is out of our control. We can only do the best that we can do.

Andrew: It's worth remembering that, before the law existed, terminally ill Victorians were taking desperate measures to end their suffering: importing illegal drugs without knowing their reliability; taking their own lives with guns, knives, ropes, and worse; and sometimes being helped by doctors acting in secret.

Michael Dooley: Bearing in mind that for me, I've seen, you know, deaths and suffering that were prolonged, and that's a worse option than putting in safeguards and mitigating most of the risks, albeit acknowledging that things can always go wrong.

Andrew: Support for what Michael does isn't universal. When the law came into effect, flyers were distributed outside his workplace by the Christian activist group Right to Life. Alongside descriptions of the Statewide Pharmacy team as 'peddlers of death' and an 'Uber-style poison service' were pictures of a black car. A black car not dissimilar to the one Michael drives.

Michael Dooley: We were expecting something. And it was interesting because we… at one stage it looked like they were personally targeting us, you know. I drive a black car, but it wasn't the case. So, we took it on board. We made sure that the team was safe and aware of what was going on. I thought it was a bit cheap, some of the stuff they said, and it was bit daggy and all of that, but they had the right to protest. And they weren't personal about it, and if they wanted to be personal, they, they knew my name, and they didn't. And I think that's pretty good.

Andrew: Michael understands the passions his work arouses. Though not overly religious, he is Roman Catholic. Aware of the Vatican's implacable opposition to assisted dying, there was one family member whose opinion was particularly important to him.

Michael Dooley: I spoke to… my dad's a devout Roman Catholic, and I asked his permission for me to get involved.

Andrew: What did he say?

Michael Dooley: He said 'yes,' because I explained to him, and he very much understands what needs to happen. Dad was very supportive.

Andrew: And as for the rest of his family…

Michael Dooley: They're proud that I do it. They don't want to hear a lot about it. sometimes my daughters will go, 'Well, are you going for a drive today, Dad?' I'll offer it up

every now and again and we'll talk about it a bit. The family knows that's what I do and they're supportive of me.

[STIRRING MUSIC]

Andrew: As I listened to Michael talk about his work, and the families of their gratitude, my mind went back five years to Liz le Noble. Blonde, 40s, sharply dressed, with a wicked laugh, Liz was a former New South Wales Businesswoman of the Year. I was making the first season of Better Off Dead, and I will never forget hearing Liz describe what it's like to be in palliative care, so doped up on pain relief you can't tell anyone it's not working.

Liz Le Noble: Floating in a psychedelic-coloured cube where you can't speak because you've got locked jaw from the drugs, you know that you are writhing around on a plastic sheeted bed, your hands, 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. But I remember thinking, 'Surely in modern medicine, modern science, I can't believe I'm actually experiencing this.'

Andrew: Liz was being treated for a very rare cancer.

Liz Le Noble: 1% of the world's diagnosis of cancer is neuroendocrine, and I had a 1% version of it, and they can't control it.

[SOMBRE MUSIC]

Andrew: The number of surgeries she had undergone was dizzying.

Liz Le Noble: Complete abdominal hysterectomy, everything. Ovaries, cervix, everything. 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.

Andrew: Liz was told that there was no cure, and all treatment would be palliative, but her experience inside the psychedelic cube left her terrified of the path ahead.

Liz Le Noble: So far, Andrew, I'm not fearful of death, still. I don't want to die, obviously. I'm fearful of that end road to death when you are actively dying. I know they can't control my pain.

Andrew: She began searching for alternatives. Plan A was the Dignitas Clinic in Switzerland, offering a painless death to foreigners in a critical need, but she needed the support of her palliative care specialist.

Liz Le Noble: And he just sat there, and he said, 'No.' And there was a big pregnant pause. That's when the real patient-doctor, 'I'm the doctor; you're the patient' level of feeling came into the room. And I was figuratively biting my fingernails, going, 'Alright, Liz, go on. Do it. 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 that. Those words exactly. So, I found that curious that it had nothing to do with me.

Andrew: Liz then moved on to Plan B: illegally importing the lethal drug Nembutal from China, but Liz was terrified of implicating her family in a crime. Here, she's discussing how to disguise the Nembutal with her brother, Jason.

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? I'd 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 *[VOICE BREAKING]* I'm fucking trying to get a strategy together!

Andrew: Even now, five years later, the despair in Liz's voice is heartbreaking.

Liz Le Noble: Do you know what, guys? I think what I've just done is I've crossed the threshold of asking too much, and whenever I started this journey, the thing I was angriest about is that I would have to drink it and be alone. But I should've just shut my fucking mouth and just gone, 'I'll do it,' and I'll just do it on my own.

Andrew: In the end, Liz never did take the Nembutal. She died in palliative care. Despite their excellent care, it was, according to her brother, an undignified death.

[SAD MUSIC]

Andrew: What happened to Liz needn't happen in Victoria now.

Michael Dooley: We are privileged to be involved with the family and the care in a really challenging time for them**.** They write us stories. They write about how it went. They will ring and share. They do that a lot of the time. We have a great big long list of all the comments that everyone has written**.** The most common word that's in them is 'peaceful.'

[MUSIC: 'LOYDIE'S ANGEL' BY JORDAN LASER]

Andrew: If you'd like to support the work of Go Gentle or find out more about us, go to our website at gogentleaustralia.org.au.

In the next episode of Better Off Dead: no threat was raised more by politicians opposing assisted dying than that of someone being coerced to their death against their will.

Male MP: Sometimes the relatives might be wanting to encourage the person to take their medicine – or take their poison, I should say.

Andrew: Meet the woman whose job it is to make sure that doesn't happen.

Betty King: I just said, 'No, remove the prisoner.' That's when he said, 'Oh, you can get fucked.' And I thought, 'That's an eloquent statement.'

Andrew: Retired Supreme Court Justice Betty King is now Chair of Victoria's Voluntary Assisted Dying Review Board. Her job? To be the guardian of the safeguards.

Betty King: It's not an easy process, but neither it should be. This is the ending of a life, and it ought to be treated in a serious manner because it's a serious thing to do.

[CLOSING CREDITS]

VO: Season two of Better Off Dead is created, written, and presented by Andrew: , with Beth Atkinson-Quinton, Martin Peralta, Kiki Paul, Steve Offner, and production assistance from Alex Gow. It is a co-production of Go Gentle Australia and The Wheeler Centre. Follow wheelercentre.com/betteroffdead to learn more about the people and ideas from each episode.

['LOYDIE'S ANGEL' CONTINUES]