Better Off Dead

Transcript for season 2, episode 5: I Choose Not to Suffer

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.

Andrew: So much was said in Victoria's parliamentary debate about the people who would choose Voluntary Assisted Dying were it to be made legal.

That they could not possibly know their own minds.

Female MP: I do not believe that an individual who is facing such enormous pressure and stress is capable of making a decision to end their own life.

Andrew: That the burden of possessing life-ending medication would be too much for them.

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 after I've watched my favourite TV show?'

Andrew: That they would be pushed into ending their lives by hard-hearted relatives.

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

Andrew: Or that they should never even need to make such a choice, because palliative care would provide for them.

Male MP: Advances in palliative care medicine have been prodigious, to the point where well-managed cases under best practice palliative care can eliminate physical pain and discomfort.

[POLITICIANS' VOICES OVERLAPPING]

Andrew: So. Many. Words.

Why don't we just let these people speak for themselves?

Meet Ron, Fiona, and Peter.

I'm Andrew Denton. You're listening to Better Off Dead.

[OPENING TITLES. VOICES OVERLAPPING]

Andrew: None of us knows how our death is going to be. All we know for sure is that it will be ours, and ours alone.

The three people's stories you are about to hear are linked by only one thing: a law that has enabled them to choose the day and the manner of their passing.

[SHIP'S HORN SOUNDS. SEAGULLS CRY]

Ron Poole: It was a June morning, bit of mist around but a beautiful day. And I will never forget the sight of that ship coming down the centre of Sydney Harbour. It's something that's been etched in my memory ever since.

Andrew: Ron Poole arrived in Australia in June 1962, a ten-pound Pom from Wolverhampton on the SS *Oriana*. It was a moment he had dreamt of for as long as he could remember.

Ron Poole: If you know anything about Wolverhampton, it's an industrial area in West Midlands. And for some reason, when I was a little child, as they asked you, 'What are you going to be when you grow up?' I always used to say, 'I'm going to be a farmer and go to Australia.' Now the two things about that are: one, I would have no idea what farming was about. Secondly, as a nine-year-old, where the hell is Australia?

Andrew: Now 77, Ron still can't explain what put the idea in his nine-year-old head.

Ron Poole: The only thing I can think of is my grandmother had two sisters in Adelaide who used to send tinned fruit to us during the war.

Andrew: But now, here he was: an Aussie farmer.

Ron Poole: Cattle and horses were my speciality.

Andrew: Five years later, he married an Australian girl. His son, Christopher, was born three years after that. A decade later, the marriage ended in bitter circumstances. Ron moved out of his home in a small Hunter Valley town in New South Wales. Christopher chose to live with his mum. At a low point in his life, a friend reached out to Ron. Her name was Sue.

Ron Poole: She was a very strong woman, a spade was a spade, and we just hit it off. We were married in '85, and in all those years we never went to bed angry.

Andrew: Ron became a stepfather to Sue's adult children. The two moved to Shepparton in Victoria and trained to become foster parents.

Ron Poole: If a girl wanted to give up a baby, she had a six-week window to make her mind up whether she definitely wanted to have the baby adopted or not. But she had to give the baby up for that time. And that's where we came in. We'd have them for six weeks.

Andrew: Even though it's only six weeks, it must be very wrenching to have to hand a baby on to someone else.

Ron Poole: It was at first, but to talk to these people who are going to adopt these babies... You know, they were beautiful people.

Andrew: At times, Ron and Sue had up to four babies in their care.

Ron Poole: I was working the afternoon shift and sometimes I wouldn't get home till one or two o'clock in morning. But up on the kitchen wall was a big chart as to which baby, when they were last fed, when they were changed and all the rest. And the babies didn't always fit the system because they couldn't understand the rules. When I look back, I think, 'How the hell did we ever do it?' But we did. And it was good.

Andrew: Older children were fostered too, bringing different challenges.

Ron Poole: I remember one little boy. When they first came to us, first thing Sue would do was strip them off, put them in the bath, put fresh clothes on them. But this little boy, we took his clothes off him and put them in the bin, that's how bad they were. But he also had this little teddy, and it was rotten, and he was hanging on to it like life. So, while he was in the bath, she put Teddy in the bath as well and washed him, and when she put clothes on him, she took him outside and put Teddy on the line. And he sat under that clothesline until Teddy was dry. He wasn't gonna part with him at all, but after that, all he needed was a bit of love.

Andrew: For some of these children, love had been in short supply.

Ron Poole: They'd come from real bad, neglected backgrounds. But once they could see that they're safe – they got a bed to sleep in, no one's gonna threaten them with anything, and they're getting fed – the dramatic change that can happen in two or three days, all of a sudden you got different kids altogether.

Andrew: Over the years, it became a labour of love.

Ron Poole: I think we had 12 pre-adoptive babies. And kids in-and-out, in-and-out, in-and-out, oh, about 30 I suppose.

Andrew: As Ron got older, they decided to stop fostering. When Ron entered his 70s, he started to experience shortness of breath. Then, in October 2018, he found out this had a name: idiopathic pulmonary fibrosis. Sue leapt into action.

Ron Poole. She said, 'Righto, we'll get everything ready so I can look after you.'

Andrew: But two months later, Sue was diagnosed with lymphoma.

Andrew: Was it a hard fight for her, Ron?

Ron Poole: Yes. And she was a fighter. I'll tell you this: she was stronger than me.

Andrew: Their medical insurance meant Sue was well looked after but, as Paul Kelly sings, 'Death doesn't care just who it destroys.'

Ron Poole: After the chemo, she really went downhill fast. From the diagnosis till the day she died was 65 days.

Andrew: That was early 2019. Ron's world was shattered. But two years later, as I look at him on my screen, I see a man determined to be positive about the hand he's been dealt. Sitting in his kitchen with an oxygen line attached to his nose, he looks surprisingly robust for a man nearing the end of his life.

Andrew: Tell me about idiopathic pulmonary fibrosis. What is it and what does it feel like to have it?

Ron Poole: 'Idiopathic' is they don't know what causes it. And there's no cure for it. It's just the lungs are getting harder and harder, and the capacity is getting less and less for the oxygen. So, it'll come to that stage where I won't be able to breathe properly by myself. I'll just be puffing, puffing, puffing 24 hours a day.

Andrew: It sounds to me like being suffocated, but from the inside.

Ron Poole: That's right. As long as I'm sitting here, I'm alright. if I just got up from here, walked across there and walked back, I'd have to sit here for ten minutes to get my breath back. I get... times I get a bit panicky because I can't get my breath at all.

Andrew: If the disease were left to run its natural course, Ron would end up in a hospital on a life support machine.

Ron Poole: If I was in your state – New South Wales – that's what would happen to me. I'd have no option.

Andrew: It was discussing this likelihood with his doctor that prompted Ron to look at alternatives.

Ron Poole: I said, 'That is never going to happen. I'm not going to be just lying there hooked up to a machine.' That's – that's not a life.

Andrew: Ron's fears were for more than just himself.

Ron Poole: I don't know how much smaller the lungs will actually get to, where even the machine couldn't pump air into them and then someone's got to say, 'Switch it off.' And I'd hate to be that person who has to say to the doctor, 'Time... time to switch it off.'

Andrew: Faced with an incurable disease, Ron decided to act.

Ron Poole: When I started getting worse, I sent off to the Assisted Dying program in Melbourne and that started the process.

Andrew: This was in late 2019. At the time, Ron didn't meet the eligibility requirements of having six months or less to live. But a year later, things changed.

Ron Poole: My specialist said, 'Ron, I think it's time.' The next step was I had to go to an independent doctor, and for two hours we went through it. I was asked a lot of questions and I had to explain why I wanted to do it and be clear in my intention. And then they send a doctor up from Melbourne and we sat here at the table for two hours, and we went through it all again, testing me out as to where I was.

Andrew: Ron was found to be eligible.

Ron Poole: The next step is then when the pharmacist from the Peter Mac hospital, they came up and see me. They also were here for two hours, discussing everything, all the pros and cons

Andrew: A Melbourne doctor wrote – very much an opponent of these laws – that they were easy to access, there was no real mental health review, 'no palliative care pathway' was the expression she used. Is that how you see things? Was it easy?

Ron Poole: No, no, I'd say exactly the opposite. So, these people haven't been through the process, right? they haven't spoken to people like myself and found out what it's all about. So, it's not an easy thing. There's a lot of checks and balances in place. You have to convince them. So that's four... six people altogether over a period of months, that you are fully understandable of what you're doing, what will happen when you drink that 30 mils of liquid.

Andrew: And were possible treatment options discussed with you?

Ron Poole: No, well they know that there's no treatment for it, because of the disease I've got, they know there's nothing can be done.

Andrew: What about palliative care as an alternative route for you?

Ron Poole: In what way? For someone prepared to go into a nursing home and be looked after 24 hours a day, that's not going to stop what's gonna happen to me. So, as far as I'm concerned, the longer I can get up, get about, and act normal – [CHUCKLES] as normal as I can – the better it is for me.

Andrew: Did you feel that anyone who you dealt with in the process was encouraging you to take this path?

Ron Poole: It was always the other way, that it's entirely my choice at all times. I can drop out anytime I like. There's no-one – not one person in the system – who has ever hinted, intimated or tried to persuade that I should use it.

Andrew: I ask Ron how he'll know when the time has come.

Ron Poole: I really don't know how bad it's going to be before I say, 'Yeah, enough is enough.' But I think I'm going to be that stage where I'm just sitting here doing nothing, and I still can't get my breath. Hopefully, I'll give people a week's notice. Gives them the opportunity to come.

Andrew: Ron had given a lot of thought to how he'd like his final moment to be.

Ron Poole: I've got it all worked out. The doctor will be there, I'll mix up the stuff, and because the drink is enough to bloody kill you – the taste of it, apparently – I've got some Limoncello that I made in the cupboard, it's pretty strong. [CHUCKLES] So that's what I've got planned. There's a couple of folders and it's got all instructions of what's going to happen after I'm gone. My friends and my stepson have been told that when I do it, I'll see them beforehand. But I don't want them there when I do it.

Andrew: I asked Ron, 'Why?'

Ron Poole: It's a private thing, in many ways. And it's just I don't know I don't want to see them there while I'm doing it. I mean, after five minutes, I'll go to sleep. They can come and see me. I won't know anything about it. But they understand where I'm coming from and as they say, well, it's your last wishes. And who's going to deny me that?

[GENTLE MUSIC]

Andrew: Five years earlier, when making the first season of *Better Off Dead*, I sat with palliative care nurse Ray Godbold, who was suffering from the end-stage cancer that killed him. His family were in the kitchen, preparing lunch, and I'll never forget the quiet way he told me that, despite all the love, dying was still a lonely experience. That thought echoed as Ron began to tell me of the things that still give him joy.

Ron Poole: My dog. [Bobby?] Bobby. Oh, he's the life and soul. My mates, when they pick me up from here, they got an olive grove out in the farm, just going out there for the day.

Andrew: His mates are father and son, Paul and Brian. When Ron could no longer drive the 1967 MGB sports tourer he bought himself after Suzy died, he gifted it to Paul.

Ron Poole: We've been mates a long time. Now, they phone me up at least twice a day, every day. And they visit me at least three times a week. Yeah, I look forward to their visits Because it does get... I spend many hours just sitting here by yourself. Everything's going

through your mind of where you've been, where you've come from, and what's in front of you. And not being able to do the things I used to do, like to do, enjoy doing, it does get to me a bit, and you do get some dark thoughts. And then you think, 'No, no, no, no. No, you're better than that.' And you get on top of it. One of the boys will phone up and you're talking on the phone and it's all gone. You've forgotten about it.

Andrew: There'll be people that listen to this who'll hear what you've just said and think, 'We can help restore meaning to this man's life so you don't feel lonely.' Would that make a difference to you?

Ron Poole: It's only a couple of times that I've got into that situation. Most of the time I'm on top of it.

Andrew: Most days, Ron gets home help and Meals on Wheels. There's also his at-home palliative nursing care. Not nurses; 'angels,' he calls them. And he knows if he wants it, hospital palliative care is there, too.

Ron Poole: I've only got to pick up the phone and I can arrange it. If I thought I needed it, I would get it.

Andrew: He still writes frequent letters to the local paper, The Shepparton News, who put him on the cover recently under the headline 'Ron's Final Choice to Die.' I asked him what the response has been.

Ron Poole: I had quite a few phone calls and emails, all positive. I didn't have anyone saying, 'Oh, you shouldn't be doing it.' The thing that got me was people saying how brave I am. I said, 'I'm not being brave. Bravery doesn't come into it.' Everyone's going to end up there one day, and if I have a choice of how you go, how many people would like that choice? Because of the disease I've got, I'd hate to be in any other state. At least I'm on the program, it's all sitting there in the cupboard. Should the time come, I can phone up the doctor and say, 'Righto, time to die.' And it's given me peace of mind knowing that.

Andrew: How long do you reckon you have, Ron?

Ron Poole: I'll be lucky with three months.

Andrew: Three months. What would any of us do with such a thought?

Ron Poole: Having the life I've had, I'm thinking, 'Well, it's a sorry way to have to go. But being a realist, and a practical person, that's the way I'm gonna go.' I don't like it, [LAUGHS, COUGHS] ending this way, but [COUGHS] excuse me – life's... life's like that. And so, 'Righto, well this is the way I've gotta go, this is the way I'm gonna go.' And make the best of it. When you've got a terminal disease, there's no rainbow at the end of this, but I'd rather go my way than the hard way.

[GENTLE MUSIC. BIRDSONG]

Fiona McClure: Well, good afternoon. My name is Fiona McClure. Lovely to meet you.

Andrew: Fiona McClure lives and works as a real estate agent in the small town of Heathcote, about 100 clicks north of Melbourne.

Wim Wansink: My name is Wim Wansink.

Andrew: Her partner, Dutch-born Wim Wansink, is a commercial builder. Like so many relationships, theirs began unexpectedly.

Fiona McClure: I had a set of gates that needed to be stripped back so they could be powder coated, and it was like five-minute speed dating. This gentleman happened to be there, and we started a conversation, and immediately there was a spark between us.

Wim Wansink: I thought, 'Geeze, she's a nice-looking girl, and she's the right age for me because I'm 69 and she's 56.'

[FIONA LAUGHS]

Andrew: That was back in 2010. 11 years later, Fiona appears on my screen as slightly built, with big, round glasses; short-cropped, dark brown hair only recently grown back; and a million-watt smile. Everything about her, from her drop earrings and round-necked navy dress to her precision with words, speaks of a woman who believes in presenting well. By contrast, Wim, stocky and with an impressive thatch of silver-grey hair, seems slightly rumpled. What is instantly clear: they make a great pair.

Fiona McClure: I needed to be the age I am to have enough experience in life to cope with Wim, with all the practical and endless possibilities that a Dutchman brings, but there's not a 'no' in their life. It's, 'Okay, how are we going to do it?'

Andrew: Wim, why do you think you go so well together?

Wim Wansink: Oh, because we don't argue. We don't hold any grudges, and we enjoy each other's company.

Andrew: You both seem – is 'matter-of-fact' a fair description?

Wim Wansink: Yeah. I can be blunt, and it doesn't always suit people.

Fiona McClure: Yes, I either look good in a dress or I don't look good in a dress, so there's no, 'Maybe, yes, oh, you look lovely, darling.' It's, 'Mmmm.' [LAUGHS]

Andrew: So, you have actually asked the question, 'Do I look good in this?' and been told 'No'?

Fiona McClure: I don't have to ask the question, I'm already told. [LAUGHS]

Andrew: Fiona's easy laugh, the playfulness between them, the fact that she looks, well, healthy: these are not what I'd anticipated.

Andrew: So, can you give me a map of your body and where the cancers are?

Fiona McClure: Yes. Started off in 2017. It was a tumour of the upper intestinal tract, and they removed that, and then I went back to real estate and normal life and fantastic.

Andrew: Normal life, only with a clock ticking loudly in the background. Every three months, Fiona would have a check-up.

Fiona McClure: And then, the end of 2019, the scans that came back, it was in both ovaries, in the lining of the abdomen, and I have a large mass in the rectum.

Wim Wansink: And in the lungs, yeah.

Fiona McClure: Oh yeah, and it's in my lungs, yeah. Minor detail.

Andrew: Minor detail! I've got to say, I was quite surprised when I first set eyes on you. You look very well.

Fiona McClure: Part of it is I'd forgotten just how tired I had got before this colostomy.

Andrew: A colostomy. Who doesn't blanch at the thought?

Fiona McClure: I must confess, the colostomy gets in your head because it's so awful, and you can't wear the clothes you wore before, and being a girl, that's a big thing.

Andrew: But it's made Fiona's life better – and perhaps longer – even as the cancer continues to do its work.

Fiona McClure: I've lost a huge amount of weight. I used to run about 72. But I'm down to 56.

Andrew: Her hair has started to grow back, but the treatment that stripped it from her has come at a cost.

Fiona McClure: The chemotherapy last year caused nerve damage. So, I have pins and needles in my fingers. If there's a drop in temperature, my left leg just goes crazy – bounces around – just the nerves. And the fire comes out of my ankles. And it's just so hard to sleep.

Andrew: The clock of Fiona's life is now more than just ticking.

Fiona McClure: To get the draught, I have to have less than six months to live.

Andrew: The draught: lethal medication Fiona is entitled to under Victoria's Voluntary Assisted Dying law.

Fiona McClure: My doctors are amazed that I'm still looking okay, but then I'm probably only two months into the six months. So, who knows?

Andrew: If I were somebody sceptical about Assisted Dying, and I met you, I would think yes, you've got cancer and that's terrible, but... but you look okay. Why would you be choosing this path?

Fiona McClure: My first husband had bowel and liver cancer. It was two and a half months from diagnosis to gone. That last 10 days was pretty horrendous, and I'm planning on the fact that will likely happen at some stage for me.

Andrew: Fiona's first husband died in 2001 when Fiona was 37. I asked her what those last ten days looked like.

Fiona McClure: He was in a very good hospital in Bendigo, had the best of medical care, but he was in and out of consciousness and he couldn't take morphine. And just such incredible pain. And then ten days of downhill and watching him because they then don't feed them and everything's turned off, and they just wait, really. He was a big man, nearly six four and pretty solid, and by the end, I could pick him up.

Andrew: As if this memory isn't scarring enough, Fiona saw the same thing happen to her father when cancer got into his bones.

Fiona McClure: My father's was three years and I don't want that for anyone. He was six foot four. And he, again, became just a skeleton.

Andrew: I asked Fiona when it became clear to her that this was the path she wanted to take.

Fiona McClure: So I had three lots of chemotherapy last year, and then to be told at the end of November that there was no other option but basically go home and smell the roses. And when your oncologist has a very sad voice, you know things aren't good. And when you look at the scans and all the masses are growing, and it's moved into your lungs, then yes, you know that things aren't good. The best hospital, I think, in Australia has sent me home without further treatment. I think that says it all.

Andrew: Why is palliative care not necessarily the right path for you?

Fiona McClure: If I have to rely on other people to toilet me, to shower me, if I can't live in a dignified way, and also if the pain is too much. The drugs don't do anything for the nerve damage. It just hurts. But if it gets to the stage that it's constant, yeah, that's...

Wim Wansink: Palliative care in the end, I think, is that you're lying there like a drugged zombie. And you might be lying there for two months as a drugged zombie. What's the point of that?

Andrew: For Fiona and Wim, the choice of Assisted Dying guarantees them something they believe medicine can't.

Wim Wansink: It's dying with dignity.

Fiona McClure: Yes, that's right. It really is.

Andrew: To get the draught, Fiona first spoke with one of the care navigators: a team of nurses and social workers who guide patients through the assessment process.

Fiona McClure: I had about an hour and a half conversation that they would explore the option, and the information that she sent me was fantastic. There was no pressure that I had to do this or told that I had to do that. Just go home and read up on it.

Andrew: After doing that, Fiona put herself forward for assessment.

Fiona McClure: I had to see two doctors. I had to give permission to my oncologist to forward all my scans, so they had access to my medical history. And the interviews were, I would say, an hour, and hour and a half each. And they can come up with other strategies. Whether it's pain strategy, or another course of treatment that maybe the oncologist team had not thought about. The first doctor gave me two other options, and I've taken them both. That's why I had the colostomy bag.

Andrew: Fiona's life, she discovered, had been hanging by a thread.

Fiona McClure: Because one of my cancers is in the rectum, we found out that if I've got a blockage, that I wouldn't make it. Literally just eating a tomato skin was enough to cause a blockage, or the skin of a blueberry. That's the precipice I was sitting on. So, the option of, 'Painful way to go out/colostomy bag. Hmm, Okay. Colostomy bag!'

Andrew: The other treatment option she used was a different form of pain relief.

Fiona McClure: Neither of them have given me a cure, but they've improved my life.

Andrew: At any time, did anyone encourage you towards VAD?

Fiona McClure: It had to be me every time. It needed to be my questions, and they – I needed to prove that it was me wanting it, rather... I wasn't being coerced. There was no benefit to Wim or anyone else if I took the drug.

Wim Wansink: I'm not even allowed to be involved because of the beneficiary potential.

Fiona McClure: But yeah, it was a big thing, that they had to see that I had chosen that path.

Andrew: And how did you prove that to them, Fiona?

Fiona McClure: The same stories I suppose I have with you: that I've seen several people die and I would like to go out with dignity.

Andrew: Is part of your thinking that you wish to farewell those who you love as you are, not as what you've described with your first husband or your father?

Fiona McClure: Yes, that's very well said. I'd like to go out in a pretty dress with a pretty pink lipstick and having just had a latte with a girlfriend. So that would be a great way to go. And still looking forward to the glass of Champagne after I take the draught. French Champagne. [LAUGHS]

Andrew: French Champagne: it's become a big thing in this household.

Fiona McClure: When we were told there was nothing more that they could do, Wim said, 'Okay, only French Champagne in this house from now on.' So, that's all it is.

Andrew: Fiona is grateful for the way her choice has been supported.

Fiona McClure: I've been very impressed with the whole process. Everyone has been kind, knowledgeable, respectful, able to discuss the options. There was no sense of urgency. It's not just something that you decide now, and it's going to be available tomorrow. There are prohibitive steps in there that will stop a lot of people doing it, but if someone really feels that they need it, it is available.

Andrew: And, for Fiona, knowing that is everything.

Fiona McClure: I know that I do not have to use it, but it's there. And that's such peace of mind.

Andrew: How are you going to know the time's right?

Fiona McClure: I've been advised that the tumours will continue to grow. Because they're all in my abdominal cavity, apart from the one in my lungs, they will end up taking up all the room there. So that will cause extreme pain, or just inability to function. And that will be the trigger for the conversations with my family and with my nurse practitioner to book a bed at the little local hospital, and then go in there and take the draft.

Wim Wansink: And the Champagne!

Fiona McClure: And the glass of Champagne. I'll pour my 30ml draft, and then you have your Champagne chaser afterwards. And then I'll be asleep within about five minutes, so it's not long.

Andrew: Fiona has planned every detail of her farewell.

Fiona McClure: I've written my eulogy; I've chosen my flowers. There's no viewing, just a nice shroud – biodegradable. I've got a plot. I've already asked for where we're going to have

the wake. 'We.' Notice the 'we'? I'll be there, somewhere. [CHUCKLES] And yes, it's all there. I'm organised.

Andrew: What may sound hyper-organised to some, for Fiona, is an act of love.

Fiona McClure: I know that I'm going to die, Wim's going to go to pieces as soon as I am. I'm trying to make it as pain-free, as simple as I can for my loved ones.

Andrew: As this matter-of-fact woman describes the end of her life, I see courage, but that's not how Fiona sees it.

Fiona McClure: I know that things are happening within my body that I can't control, but I will continue and put on a pink lipstick and a pretty dress and live life as long as I can. There's no bravery; I'm just ignoring it.

Andrew: Sometimes, though, the mask slips.

Fiona McClure: Some mornings I wake up and it's very hard to get going, and it's –

Wim Wansink: Sometimes it gets on top of you.

Fiona McClure: Yeah, it does, and it's just too difficult. But then I'm a glass half full person. Before Christmas I thought it could have been any day. But, you know, I'm feeling good now.

Andrew: Wim, you just said some days it gets on top of Fiona. What do those days look like?

Wim Wansink: Oh, it never lasts long. She'll have a bit of a weep and then she'll say, 'Well, I'm over it.' And she moves on because she's a very, very strong person.

Andrew: You're both very – as I said before – matter-of-fact and there's a lot of laughter. When do you allow yourselves to reflect on life and in mortality?

Wim Wansink: Oh, it sort of creeps up on you.

Fiona McClure: Wim gets very sad, so it's no good for Wim if I get too sad because he gets in the doldrums and he can cry at the drop of a hat. So, I try to be upbeat because there's nothing we can do to stop this. I'm here, I'm going to enjoy the time I have.

Andrew: Well, I admire your strength of character, and that's what you were saying Wim, that Fiona's a strong woman.

Wim Wansink: Yes. [SOBS]

Andrew: I can see now that Wim is crying. Covering for his tears, Fiona slaps his thigh, as if to say, 'It's alright, I'll be strong for both of us.'

Fiona McClure: Wim needs to be looked after. And that's – as I said, I'm not going to be around to look after him – well, we don't know who's going to check out first. You never know in life. And I have a goal. I want to be here another seven years, so that's my plan. So even though the scans show that everything is on the move, and it doesn't look good, I don't want to know the day that I'm going to die yet. I intend that to be the best part of seven years away.

Andrew: And when it comes, how does she see that final day?

Fiona McClure: Hopefully we can have some good music, but it will be a case of having admitted that it's just too painful. And it will mean having told my sister and my mother what I plan to do. So, for all my planning, it will be sad.

Andrew: Do your mother and sister know that you have the draught? And what is their view of what you're doing?

Fiona McClure: Total support. They're only regretful that it's not available in New South Wales, and that it wasn't there for my father.

Andrew: What stays with me about Fiona: her complete lack of self-pity.

Fiona McClure: So, there's really nothing left on my bucket list. I've got a gorgeous husband, I've got a beautiful garden, I've got beautiful roses. Heathcote's a lovely community. Yeah, can't ask for more than that.

[GENTLE MUSIC]

[CROWD CHEERING. FAST DRUMBEAT]

Peter Jones: I went to see a school concert when I was 12 – Max Meritt and the Meteors – and I was just transfixed. And I thought, 'Man I want to be that guy.' Got a guitar. And I've basically been a muso for most of my working life.

Andrew: The first thing that strikes me about Peter Jones – better known as Frankie to his friends – is that he's straight-up likeable; the kind of bloke you can imagine having a drink and a good yarn with.

Peter Jones: I had a band called The Real McCoys, and we were sort of a hard country rockabilly band, and we used to play at Inflation nightclub in Melbourne, but it didn't start till 1am. So, we'd get a lot of other musos who would come after their gigs and come and sit in with us. You just didn't know where the night was going to end. Those gigs were pretty special for me.

Andrew: The second thing that strikes me: he's struggling. On my screen, he's propped up against pillows; there's an oxygen line snaking up his chest, around the back of his head, and into his nostrils; his face – like his thinning white hair and goatee – is so pale it all but bleeds

into the white wall behind him. For the hour that we are online, it is clear that simply talking is hard work.

But what I'm most conscious of is that the hour he is giving me is one of very few he has left. That's because Peter knows exactly what day he's going to die, or, as he puts it:

Peter Jones: Taking off on the 28th of this month, which is March. It's a Sunday.

Andrew: That's just three weeks still to live. Five hundred hours left in a lifetime.

Peter Jones: When you tell someone, 'Hey, guess what I'm doing on the 28th?' I usually have to hang up and ring him back in a day or two.

Andrew: How did the former front man of the Real McCoys find himself, at 66, in an aged care facility 30 minutes' drive from Melbourne's CBD, measuring the last days of his life?

Peter Jones: Well, I was born with chronic bronchitis, and I grew up in a family who smoked, and I was a smoker as well. About 15 years ago, I got diagnosed with emphysema. It's been a gradual slip slide since that period.

Andrew: A slip slide that goes by the name of:

Peter Jones: COPD, which is chronic obstructive airway disease.

Andrew: Can you give me a sense of what it feels like to be you on a day like today?

Peter Jones: Normal day, it's like walking around with a straw in your mouth for the whole day, trying to suck in enough air. That's the closest I can get. It affects every part of your life. Like doing my teeth, I get exhausted. Changing my clothes. Having a shower, I've got to take in oxygen.

Andrew: Peter started thinking about Assisted Dying a couple of years ago, before Victoria's law had come into effect.

Peter Jones: I was at a palliative care hospital. I'd gone in there with another bout of pneumonia, and things weren't looking too good in terms of coming out of there on two feet rather than in a plastic bag.

Andrew: He contacted Melbourne doctor, Rodney Syme. An outspoken advocate for Assisted Dying, Dr Syme had openly admitted to illegally supplying life-ending drugs to terminally ill people who were suffering. Peter had a question for him.

Peter Jones: If he could help me when I was at that stage where I didn't want to pursue my life any longer. I didn't want to go through the same suffering.

Andrew: Dr Syme said he would help, but Peter began to think of his daughter Hayley.

Peter Jones: She's a lawyer, she's in her 30s, and she's never given me one day of grief. Yeah, I've never had to worry about her for one day in my life. She's the love of my life, yeah.

Andrew: For Peter, the risk of acting outside the law, and of involving Hayley in that, felt too great.

Peter Jones: Being a lawyer could place her in a difficult situation.

Andrew: So, Peter shelved his plans and was discharged from hospital.

Peter Jones: I had another bout of pneumonia again and back into palliative care. Stayed there for six weeks.

Andrew: It was a familiar, grinding cycle of illness, one that had lasted for years.

Peter Jones: In and out of hospital, going into one place to get you back to a reasonable level of health, and then within three months, you're back to where you were.

Andrew: How helpful has palliative care been to you and did you consider it as your option, rather than VAD?

Peter Jones: In my experience, palliative care was not great. Getting your message across, especially to doctors, and I know they do a great job, but it was getting more difficult to. If you want more drugs to alleviate pain or relieve the symptoms, it was always a fight to try and get extra things, and it shouldn't have to be like that. So the thought of whizzing out of hospitals and palliative care wards till the last just doesn't appeal to me at all.

Andrew: Peter had looked at all the other alternatives too.

Peter Jones: I couldn't do lung reduction surgery because of where the holes are in my lungs. I wasn't interested in doing a lung transplant at 60. It's just a high infection rate, mortality rate, a long recovery rate.

Andrew: I asked what life would look like if the disease were left to run its course.

Peter Jones: There's no cure for it. Your lungs don't regenerate. There's only one direction that you have: your health can only go south. I would be, probably, bedridden the whole time, massive amounts of morphine, anti-psychotics, I'm on antidepressants as well. It's not a life I find attractive at all. So, I made a call to go this way.

Andrew: To support his application, Peter had long-established medical relationships to call on.

Peter Jones: I have a long history with my lung physician, and he has more than 15 years of x-rays and lung function tests that show a steep decline every time I go, to the stage now where the last time I saw him, he said, 'Well, you don't need to do any more lung tests because there's nothing there to test.' So, I ended up getting a second opinion from another

specialist who made their own observations and I was fortunate enough to get the support from those specialists, and my local doctor who helped guide me through the process.

Andrew: Would you describe it as a thorough process?

Peter Jones: Yeah, it's very thorough. There's no little loophole that you can jump through to try and swing the system in your favour. Every dot's got to be there, every T's got to be crossed. If it's not, they just send it back until it is.

Andrew: At any time, did you feel that anyone was encouraging you to follow this path?

Peter Jones: No, no-one's ever suggested to me that this is what you should be doing. That's never occurred. It's a path that I've looked at for a long time, so I'm quite prepared for what lay ahead, y'know.

Andrew: Did anyone remind you that you didn't have to do this if you didn't want to?

Peter Jones: Yeah. I get told that regularly by my GP and also the VAD navigator, just because I've signed on and have the medication. It's always been told to me that I can send it back.

Andrew: You mentioned before you're on antidepressants. Again, people that oppose these laws often paint a picture of people like yourself who wish to end your life, doing so primarily because you're depressed. Do you believe it's had any effect on your decision?

Peter Jones: No, it hasn't had an effect on my decision. My COPD was well advanced before the depression issue was discovered. That was a depression that existed since my early teens, but I'd never recognised it. And I spent a good 20 to 30 years of my life with real highs and lows, and the medication that I was put on just put everything on a more even keel.

Andrew: As we're talking, my mind keeps coming back to that date.

Andrew: How did you choose March the 28th?

Peter Jones: I spent weeks trying to figure out a date. And I'd get a day in my head and it'd be like, 'Oh, I'm away that week. How about the week after?' Or, you know, I'm a very accommodating person. 'Oh, yeah. Well, I suppose I could, you know, ah, bring it forward a week. That's no problem.' It was just going on and on. And the doctor said to me, 'What are you doing? You just bloody make the date and they fit around you, that's how it goes.' Which was quite true. And I figured, look, it's going to be hard whatever day it is, so just pick a day. So that's what I did. It's a Sunday. It'll be just after lunch.

Andrew: How was it for you telling people?

Peter Jones: My family was difficult at first, and as you know, you only have a handful of really good friends in your life. I've told them. But beyond that circle, I've kept it to myself because it's very demanding on your time. There's no advantage, I think, to tell people it's

going to happen. It will only make them more distressed. Trying to sum things up in a nutshell with people on the phone and it's like, too hard.

Andrew: Did anyone you tell struggle with your decision?

Peter Jones: Everyone's been taken aback, although not surprised.

Andrew: Peter has found that one of the advantages of knowing the date is that you can plan for it.

Peter Jones: It's been good 'cause you get to write your own eulogy. Funeral's already been organised. I've got the black Cadillac coming to take me away. I actually had a ride in it beforehand, took it for a test drive. It's a ripper. A big V8 warble. This guy imported the car from California and it's a purpose-built hearse, straight out of the Munsters, it is. It's black and the rego's RIP.

Andrew: You said before that you're focusing on enjoying life as much as you can. What are the things that are giving you joy?

Peter Jones: It's been good catching up with people, although it is tiring. Sleeping, staying up late and watching movies about World War Two. Don't ask me why; Hitler's got in my brain the last three weeks, and I've been watching everything from 'Hitler's Underpants' to 'Hitler's Career in the Boy Scouts.' It's just endless material there. So yeah, that's been fun.

Andrew: I ask who'll be with him on the 28th.

Peter Jones I'll have seven people here on the day with me; family members and their partners, and my daughter, of course, and her mother. I'm going to send off with a song called 'Sleepwalk' by Santo and Johnny. It's a pedal steel and guitar instrumental. I'll speak to everyone individually for a couple of minutes, and then those who want to come in while I have the medication are welcome to come and sit with me. And then that'll be it. I'll be off.

Andrew: How often do you think about the 28th? I imagine if I was in your position, my mind would be travelling there quite a lot.

Peter Jones: I've been kept pretty busy. Organising your own funeral takes a lot of work. [CHUCKLES] I don't look really towards a date. It'll come when it comes, and I'm just trying to enjoy the time I have left.

Andrew: And then, hesitation. It turns out there is one thing about the 28th Peter has been thinking deeply about.

Peter Jones: I'm still a bit – you might be able to help me, Andrew – I'm still a bit confused about this. Yeah, the end-of-life situation, when people take the medication. What I've read is, you know, the family gather 'round and it's a really lovely moment and everyone's happy, and I'm sort of looking at that thinking, 'I can't see it as a Kumbaya thing.' You know, I imagine it's a bit darker than that.

Andrew: It's different for everybody. Some people I've spoken to describe it kind of as a Kumbaya thing; it's very beautiful. Some people are really distressed by it. Some people find it very hard to get their head around the knowable finality of it, like just going to happen on this day at this hour. It's very different for each family, for each individual. I imagine you're asking that because of your own family?

Peter Jones: Especially my daughter, yeah. I mean, my brother and sister, everyone's very supportive. They understand it. It's taken a while for it to sink in, but they all get it. They know how crook I am, how much I struggle. But my daughter's going to lose someone she loves very much, as I am. That's my biggest fear. I don't know how I'll deal with that at the moment either.

Andrew: It is such an understandable fear.

Peter Jones: Actual death itself, I'm looking forward to, because no more suffering. But saying goodbye to those people who love you the most... that's going to present a few issues, I imagine.

Andrew: When you've spoken to Hayley about this, how has it been for her?

Peter Jones: Very difficult. I can't talk at length about it. I've had to sort of just give her little chunks to bring her on board with organising funerals, and this and that and the other. But I can't go too deep with things, because we both get very emotional. But that's getting better as the day draws nearer. I think she's starting to get her head around that, that it's actually a reality now.

Andrew: I think it is very difficult, but if this helps, I do believe, from the majority of people I've spoken, that whatever the range of emotions, there is – particularly in a family like yours where there's nobody who's at odds with your decision – that it is also a moment of intense love. Strip back to that.

Peter Jones: Yeah. Yeah. Okay. That's good, good advice and a good angle there.

Andrew: You and Hayley, that's, I think it's fair to say your most important relationship, yes?

Peter Jones: Yes, sure is.

Andrew: For you and Hayley, if it helps to think about it this way, yes, it is the end of your life, but it is a moment of unvarnished, absolutely honest love between the two of you, and there is nothing in between that moment for you.

Peter Jones: Yeah. Well said mate, well said. I'll keep that on board.

[SAD MUSIC]

Andrew: As I write this, it's now March 16th. Peter has 12 days left to live, and the heartbreak about Hayley in his voice will not leave my head. Whatever Assisted Dying may be – painless or peaceful, beautiful or merciful – it is no golden ticket. You still have to say goodbye to your one wild and precious life.

[SAD MUSIC CONTINUES]

Peter Jones: In my, my own mind, I've had a good life. I've got a wonderful daughter, I've made some great friends. You know, I've made records, I've written plays. I've done everything that I've ever dreamt of doing as a kid. You know, I haven't left anything behind. And I think I'm a good person. That doesn't sound like much, but to be a good person, it doesn't take a lot of effort, and it makes a big difference to people's lives.

Andrew: Do you reckon anything's on the other side?

Peter Jones: No, mate, I think once it's over here that's it. But hey, if there's a hole out there that takes you to a new world, great.

Andrew: Peter, I really appreciate you giving me an hour of your precious time. I hope the next few weeks are good weeks for you.

Peter Jones: Thank you very much, Andrew. Thanks for the opportunity, mate.

[MUSIC: 'SLEEPWALK' BY SANTO AND JOHNNY]

Andrew: Two days after finishing this episode – ten days before Peter 'takes off' – an email arrived from him out of the blue. He'd heard I'd been crook. Wishing me a speedy recovery, he wrote, 'I thought I'd cheer you up with some artwork of mine that is the back page of my funeral program.'

Then, a hand-drawn picture of two dancing skeletons, male and female, dolled-up to go, martinis and cigarettes in hand.

Above them, the words 'Till death do us party.'

[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: the pharmacists who deliver Victoria's life-ending medication.

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'?

Andrew: How do you hand someone medication knowing it will kill them?

Michael Dooley: We've all been in circumstances where we've sort of had to eyeball other pharmacists, then go, 'Can you take over for a few minutes?'

Andrew: Who are the people they meet?

Michael Dooley: They're at the end of a long journey and they know exactly what they're doing.

Andrew: And how do they say that last goodbye?

Michael Dooley: There's no easy way, you know. It's not a normal goodbye.

[CLOSING CREDITS]

VO: Season two of Better Off Dead is created, written, and presented by Andrew Denton, 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]