Episode 8 – Darkness visible: Marjorie, Edith & Laura

[SUICIDE WARNING]

[PRAYER BELL CHIMES]

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

Laura: I've had enough of all this. It feels like nothing gets to me anymore. It's like I'm dead inside. I've tried, I've really tried. But I just can't. It keeps feeling empty whatever I do, and pointless.

Andrew Denton: This is 'Laura'. She lives in Belgium and, after years of mental suffering, her request for euthanasia has been granted. Laura is just 24 years old.

[OPENING TITLES]

Andrew Denton: My name is Andrew Denton and you're listening to *Better Off Dead*. When I set out to learn about assisted dying, I told myself that I wouldn't look away from any of it, no matter how hard. This determination was shaken when I learnt of Laura.

Immediately, alarm bells went off.

My gut reaction was, "A 24-year-old who's not terminally ill? How can they be so sure they can't help her? Surely there's a point at which a society goes, "No, you have too much life ahead of you for us to help you die"?

If you asked me, "Where is the line where it got uncomfortable?" this was it.

To me, this seemed unacceptable. Dangerous.

The days that followed, talking with some of Belgium's leading psychiatrists and physicians, were amongst the most intense I've ever experienced.

Emotionally, I couldn't shake the thought, "This doesn't seem right," but intellectually I wondered, "Is there more here than I know?"

As I was grappling with it, I rang my wife in Australia. I told her about the young woman and what I had been learning about why doctors here thought it allowable she be granted the right to euthanasia.

To my dismay, she responded fiercely. "I support assisted dying," she said, "but this is not right. You've drunk the Kool-Aid on this, Andrew".

Sitting in my hotel room in Brussels, late at night, I wondered if she was right. Was my belief in assisted dying blinding me to something that was fundamentally wrong?

Maybe this really was the slippery slope?

To be honest, I toyed with not including this story in the podcast: It is so fraught with ambiguity and nuance that I feared it could easily be misunderstood and derail everything else I've been arguing.

But two things persuaded me to keep it in: First, that it was the people who were treating this young woman who had alerted me to her case. They wanted me to look at it – to try and understand. I realised that, if I was going to be honest about the case for assisted dying, then I had to give everyone the chance to hear what I had heard – no matter how confronting.

And, second, a meeting I had, two hours' drive from Brussels, with a man whose sadness was so intense it was almost visible.

The story he told would change my understanding of the world.

Andrew Denton: Before we get to that story, and the case of Laura, a question: What if it turns out that the offer of euthanasia actually saves lives?

Marjorie Vangansbeke: My childhood was – actually a lovely childhood! Living in Oudenaarde, lots of green, lots of friends. Being playful, doing naughty things, building camps… actually a lot of things outdoors, lots of sports. Good people around you.

Andrew Denton: Margery Vangansbeke's early years sound idyllic. As she grew up she took on the life of an adventurer.

Marjorie Vangansbeke: I'm a pilot as well. I do scuba diving. Now I've become a cook. It's interesting and it never stops, this constant curiosity. There are things you do – actually you can do by yourself; you don't need anyone else.

Andrew Denton: Doing things by herself was important to Marjorie because, from an early age, she struggled to connect. By her mid thirties Marjorie's isolation from other humans had deepened to an alarming degree.

Marjorie Vangansbeke: I had no communication I think for six years. I lived completely by myself, no communication – so even the way you think, speak, isn't right any more, compared with your age.

Andrew Denton: Can you describe to me why you felt you had to spend those six years within yourself?

Marjorie Vangansbeke: I think it was the communication with other people didn't work, because each time you bump into walls and then it's like OK. You are very sad by yourself, and if you do it for so long you have no realisation anymore what you're really doing. So you hide really.

Andrew Denton: You get locked in your own sense of yourself.

Marjorie Vangansbeke: Yes.

Andrew Denton: How about your family? Were you able to talk with them?

Marjorie Vangansbeke: I had no communication with them.

Andrew Denton: You couldn't talk to them or you felt they couldn't talk to you?

Marjorie Vangansbeke: I think it's both ways. It goes both ways. I couldn't talk to them, and actually they ran away. Run away – yeah, that's a very good way of defence.

Andrew Denton: So they could see the change in you and they didn't know how to approach that?

Marjorie Vangansbeke: Yeah, that's it.

Andrew Denton: Marjorie couldn't make herself understood to others and she couldn't understand why they shunned her in turn. To help her break out of the cage in which she was trapped she sought psychiatric help.

Marjorie Vangansbeke: I was treated by a doctor between 34 and 40 years old. Evolution was just like going downhill and I said, "Well for six years you as a professional within your trade as a doctor, you cannot help me any further. So if you did, as a professional, everything you could, then we both know there is no hope and I will not accept to live".

Andrew Denton: Did you have anyone you were close to in your life?

Marjorie Vangansbeke: Not in those six years. Before then, yes.

Andrew Denton: So by the end of that six years you had in some ways made yourself a ghost?

Marjorie Vangansbeke: Yes, I'm pretty good at that.

Andrew Denton: Marjorie was alive but hardly living – an invisible being alienated from her friends, family and community. If this was life, she'd had enough.

Marjorie Vangansbeke: I just went for, "OK, we'll do this – euthanasia. It's over and done". Because if you are in that negative spiral, you don't see anything clearly, it's painful. It's like my body hurt without any reason, because I wasn't ill. It was just ligaments, muscles, even your skin, like everything was "Ow". Just mentally completely worn out, a wreck. Yes, a wreck. You don't want to live like that.

Andrew Denton: Do you remember the moment where you went from being in pain to thinking, "I want to end this"?

Marjorie Vangansbeke: Yes, I recall that, and it was like, "Phew, I have the address. I will drive there, ask for euthanasia, and it will be all fine. It's over".

Andrew Denton: What happened next?

Marjorie Vangansbeke: So I went to ULteam in Brussels, a location where you can ask for euthanasia.

Andrew Denton: ULteam is a specialised medical unit that deals with difficult end-of-life requests.

Andrew Denton: When you applied for euthanasia, were you told, “Yes, this is possible, but first you have to do these things”?

Marjorie Vangansbeke: There was not a clear yes or no. It was just more an introduction the first time. I didn't speak much then. I remember it was Dr Thienpont asked me certain things, then I go, “Here, it's all written down here. Here. Just read that”. I said, “But I do want to have a conversation with you”. But if you don't speak for six years, it's – the way you talk is – it doesn't sound good. I mean you're slower in your talking. You have to think more. Also your structure in what you say is chopped.

Andrew Denton: Your own language has become a foreign language.

Marjorie Vangansbeke: It was. Yeah.

Andrew Denton: team psychiatrist dug deep into her life and psyche. The result was not the free pass to death Marjorie had been hoping for.

Marjorie Vangansbeke: She gave me a card with three points. One was research Asperger's syndrome; two was a psychologist to visit, kind of to speak about Asperger's to get more insight of it; and then there was a next appointment at ULteam in Brussels. I was really not pleased with them. Because it was like, “Oh no, there we go again, another title – from psychosis to Asperger's. And I looked it up – Asperger’s, OK – internet, library, some books, and it was funny. I really had so much fun reading it – because it was me.

Andrew Denton: Under the guidance of ULteam , Marjorie was sent to group therapy to better understand her diagnosis of Aspergers.

Marjorie Vangansbeke: And most of them are Asperger. I mean you recognise it like that. But I didn't go right from the start when I knew. It took six months to find out – because if you read it, it's funny, but what does that mean?

Andrew Denton: Marjorie learnt new skills to help her navigate the world.

Marjorie Vangansbeke: What do I have to avoid and not do is also very important. That's what I've learned the last year now – what not to do. So there are steps you have to do by yourself, and they worked.

Andrew Denton: So you came to ULteam , you were given Asperger's to research, you saw yourself there, you spent six months working on things that were suggested to you. Were you still interested in pursuing euthanasia?

Marjorie Vangansbeke: No, it's that time I went to the group, and I see all those other people and I was thinking, “I am not alone”. That's how it went and it worked out really good.

Andrew Denton: If you hadn't applied for euthanasia, which led you to the diagnosis of Asperger's and the chance to learn to be in control, what do you think might have happened? What do you think you might have done?

Marjorie Vangansbeke: I probably would have committed suicide.

Andrew Denton: Under Belgian law, permission for euthanasia can only be granted if "the patient is in a medically futile condition of constant and incurable physical or mental suffering that cannot be alleviated".

In the case of psychiatric suffering, three doctors, one a psychiatrist, must independently come to the same view that the case is so intractable that the request for euthanasia can be granted. And this only after all possible treatment options are canvassed.
There is another important safeguard too – the patient has to be mentally competent to make a request. But how does that work when someone has severe psychiatric illness?

Lieve Thienpont: If we are not sure that they realise very well what they are asking for, then we are very, very careful of course.

Andrew Denton: Lieve Thienpont, 63, is a psychiatrist who works at ULteam.

Lieve Thienpont: And sometime, for example with patients who are psychotic or almost psychotic, we will not help with euthanasia. We have to be sure that they know exactly the consequences of euthanasia, the consequences of the question.
Andrew Denton: It was Lieve who saw Marjorie and who directed her towards a diagnosis of Asperger's.

Lieve Thienpont: It's because of autism they have other problems. They are depressed. They have no social contacts, they are isolated – financial problems. And for autism there is no solution – a real solution. It's clear that most of them are very intelligent. So they know that there is not much prospects, and they don't want the quality of life they have. So after years and years of looking for solutions for their depression – being in hospital, a lot of medication, electro-shocks and so on, they want to die, they want to stop their looking for solutions.

Andrew Denton: Lieve has worked with ULteam since it was established in 2011 to deal with the most complex euthanasia requests.

Andrew Denton: What are the kind of psychiatric illnesses that people come here with?

Lieve Thienpont: All kind of illnesses, but I did research from 100 patients and all of them are chronic – long history of illness, many treatments, most of them have also problems – social, economic – so there is chronic suffering. Many of them are less or more therapy resistant. That's the most important problem.

Andrew Denton: Many of the patients Lieve sees have multiple problems that, collectively, make their suffering so unbearable that they request euthanasia. Even so...

Lieve Thienpont: Most of the people don't want to die. They want to live, but they don't want the life they have. They are alive but they don't have a life. And they want to change it, most of them, and so some of them are very grateful afterwards, that they find another way.

Andrew Denton: Many, it seems, do find another way.

Lieve Thienpont: More than 50% of the people asking for euthanasia are finding other ways, and sometimes we can help to open ways because they can speak about their wish to die. It's

totally different with suicide, because with suicide thoughts they are sitting in a corner alone. They don't want to speak about it. With the euthanasia question it's totally different. It's the opportunity to speak with them and to look together if we can find better solutions, and often we can.

Andrew Denton: Those who argue the slippery slope about Belgium, point particularly to the rising numbers of psychiatric euthanasia cases. From zero when the law first came in, in 2002, to a reported 58 cases in 2011 – a number that, in 2013, increased to 92. What those statistics don't show is the number of people for whom the process of applying for euthanasia helped them find another path. People like Marjorie.

Marjorie Vangansbeke: In my case it was a gift. It's priceless, what happened there, just realising what your condition is. And it's not just – the right diagnosis is fantastic, but then you have something to work on.

Andrew Denton: Marjorie' s story gave me pause for thought but, still, I was confronted by the idea of 24-year-old Laura being legally granted the right to die. Even more, when I discovered a 2015 research paper Lieve had published in the British Medical Journal.

Andrew Denton: You say in the report here that "the concept of unbearable suffering has not yet been defined adequately and that views on this concept are in a state of flux". Can you give me a sense of what the different views are within your profession about unbearable suffering?

Lieve Thienpont: Well I think one of the important questions is: is it something that we can make more objective?

Andrew Denton: How do you mean by objective?

Lieve Thienpont: It's not…

Andrew Denton: Something you can judge from the outside?

Lieve Thienpont: Yes, yes, and I believe we cannot. We cannot. So it's very subjective. It's – only the person himself, who can decide if the quality of life is acceptable or not. But we are doing now a new research just to describe unbearable suffering. How does that suffering look? For example, almost all of them will tell you that it's chronic, for example, or almost all of them will tell us that the consequences are very, very bad – social, economic, psychological. It's not only the illness but the consequences of that illness that makes the quality of life.

Andrew Denton: You say in this report in your conclusion that unfortunately there are no guidelines for the management of euthanasia requests on the grounds of mental suffering in Belgium and taking into account the ongoing fierce ethical debates, you say 'It is essential to develop such guidelines and translate them into clear, detailed protocols that can be applied'. What are your thoughts on the kind of guidelines that are needed?

Lieve Thienpont: First of all, if we offer a new therapy we must know that it can be or there is a big chance that it is successful, because in psychiatry you can always find something else

to do but we have to know that it can be really successful for a long period, not for one or two days but for longer periods. So that's the first condition.
The second is that the patient – it must acceptable. The patient must have enough energy left to go that way for the new treatment and in a time that is acceptable for the patient. I give you an example. I am thinking about a young patient, about 30 years, was 10 years in the same hospital for anorexia. The hospital was not specialised in it, not at all. So after 10 years' hospital you can say – and we did it, "There are hospitals who are better, who are more specialised in your problem, so please try it, and try it but not for one month. It takes, again a year, two year, three year. We know it's a very severe problem". So it depends on the patient. If there is energy left after all those years to try another way for, again, many years.

Andrew Denton: Because, as you said, there's not an agreement about what unbearable suffering and there's not clear guidelines about how to act...

Lieve Thienpont: No, you say it's not clear. I think it is clear – unbearable is what the patient can't bear any more.

Andrew Denton: OK.

Lieve Thienpont: Yes, so that's clear. But how that suffering looks like, that there is much more work to do to describe it.

Andrew Denton: Because this is such a critical – a crucial thing, life and death – that without clear guidelines it feels to me there is a danger there for you and for vulnerable patients.

Lieve Thienpont: Yes, let us say that in another way. Of course we are working very hard on the guidelines and we are developing them but till now they are not written down as guidelines. We are all working in a team – so a team with psychologists, oncologists, psychiatrists and so on, so we are all together working on those guidelines, but not – at the moment we don't have them written down.

Andrew Denton: Despite Lieve's explanation about developing written protocols to guide physicians in these cases I remained uneasy. How can they know that a patient's psychiatric suffering is unbearable if they don't know what that looks like?

Luc Proot: We wanted to learn – what are the factors that can convince us that the physical or mental suffering of the patient is indeed unbearable?

Andrew Denton: Luc Proot, a retired oncologist, has studied unbearable suffering in both cancer and psychiatric patients. He is one of many professionals at ULteam responding to requests for psychiatric euthanasia.

Luc Proot: There are non-psychiatric physicians, like me, there are psychiatrists in the team, there are psychologists, there are lawyers, there are nurses, there are spiritual caregivers etc etc. It is a team of 12 to 14 people. We discuss all difficult cases again and again and again. It can take months, even more than a year, before we come to a final conclusion, certainly in that kind of patient, in a psychiatric patient.

Andrew Denton: Luc has been part of the team managing Laura's case for the last 14 months.

Andrew Denton: There is obviously quite a lot of publicity and conversation about this young girl who is going by the name of Laura, who is 24. That, to the eyes of somebody outside of this country, seems like a very shocking thing – that a 24-year-old may wish to die and that that would be allowable according to the law. Can you explain something of this case and how that conclusion has been reached?

Luc Proot: It is an example of the terrible mental suffering that even young people can have, and certainly it started when they were very young. Even that young person is in treatment for more than 15 years, even that young person. And she has had all kinds of treatments and their physicians tell us that she is resistant to treatments. And today after many discussions the clarification is favourable, but if she will come to euthanasia I don't know.

Andrew Denton: By "clarification" Luc means the assessment of her case – one that led to her request for euthanasia being granted.

Luc Proot: Before taking this decision it took us a whole long process, it is not only about the medical history of the patient, it is also about his life history, and certainly, for example, in psychiatric patients, if you talk to them, you learn that they are treated for many years – 10 years, 20 years, 30 years – that they have all kinds of treatments, not only medication but also all kinds of psychotherapy.

They recovered, they relapsed, they start again the treatment, they recovered again, they relapsed again, but we see that the time between the recovery and the relapse shortens. And at a certain moment there is no recovery anymore and they are in a continuous state of mental distress, mental suffering, and that is the moment that the death wish is born. I am an oncologist from in my former life before I retired, and what I see – the difference between a cancer patient and a psychiatric patient is not very great. You see, in a cancer patient he recovered, relapsed. We give him a second line of chemotherapy, he relapsed again. We give him a third line of chemotherapy, knowing that his chance of recovering is smaller and smaller. And at a certain moment we have nothing any more, and we accept that that terminally ill patient may request euthanasia.

The difference between that cancer patient and the psychiatric patient is the outside. In the cancer patient who is terminally ill you see the patient. He is much thinner, he has pain. But the difference is the psychiatric patient has also pain inside. On the outside it's a normal person. And that's the difficulty. But the pain is sometimes worse than the pain of cancer patients. That's very difficult to understand and to say that to other people.

Andrew Denton: A key to recovery, experience shows, is reconciliation.

Luc Proot: We learnt that if we can reconcile the patient with her family, with her friends, with her life, that kind of rehabilitation is very important. They need a whole network around them. Because in their mental suffering they lose their social network, and that's one of the reasons why their mental suffering is so terrible.

Andrew Denton: But it's a fine line: For vulnerable people like Laura, the possibility of coercion has to be considered.

Luc Proot: We have to be very careful because it could be, it could be an external pressure on her in the direction of euthanasia. And that we will avoid. We have discussed with her that

she has much more to think about herself, let the outside world outside stay under treatment – it's very important for us – and try to find some courage and come to a final decision – tomorrow, next year, in 10 years – I don't know.

Andrew Denton: Is she comfortable with her decision right now, that that's what she wants?

Luc Proot: I don't know. It is up to the patient to decide whether or not they will have the euthanasia. And what we see now is that the whole attention given to her, gives her new courage, and I'm very happy for that, because perhaps she will wait, she will put her euthanasia on hold. From that point of view, I am happy that the world is looking to that case. She told me, "I am happy because people now will understand a little bit what mental suffering is"..And we work together with her psychiatrist and yeah, she is still in treatment. I think that we have still a chance to keep her ongoing.

Andrew Denton: Regardless of what a law says, should a society be letting a 24-year-old person go who doesn't have a life-threatening illness, a terminal illness?

Luc Proot: But it is a life-threatening disease, That's what the outside world don't understand. Psychiatric disorders are life-threatening diseases. That's what they call a taboo, still a taboo, and we try to, first of all, to other physicians when we were speaking with them to break open that taboo.

Andrew Denton: I think one of the things that people struggle with – probably I struggle with – is I accept that she has great pain in her 24 years of life, I do not doubt that, but what I struggle with is the thought of the life story that she may never have – of the life ahead with children, lovers, life changes. So that is a hard thing to reconcile to.

Luc Proot: Yeah, but that's your opinion. I mean that's an opinion of a not psychiatric patient. For her, her future is only mental suffering. Mental suffering. No possibilities of a definite cure – also important. They know that. They don't think about children, a life with a husband and children. Some of our patients have been married but it was a disaster. Some have children but it was a disaster – for the children.

Andrew Denton: On one level, I understood what Luc was saying. But on another, as a parent, I struggled with the thought of my child choosing euthanasia when they had a non-terminal illness. I asked Lieve if she found it hard to reconcile that thought too.

Lieve Thienpont: Of course, of course. I also have children. It must be terrible, but I saw now parents – more than one, that they are saying, "Losing your child is terrible, but looking at your child in pain, year after year, if it's possible, more painful".

Andrew Denton: On a little laneway in the country, a couple of hours out of Brussels, lives a man who carries a sadness so palpable, it is as if you can reach out and touch it.

Pierre Pol Vincke has a special insight into what is meant by unbearable and untreatable psychological suffering. His daughter, Edith, committed suicide at the age of 36, after 18 years of just such suffering; on a scale that is frankly very difficult to imagine.

As we moved away from the buzz of the garden bees and into Pierre's lounge room, we were enveloped by a profound and gut-wrenching silence – the silent hell of a father's world, beginning when his daughter was just 17 and became anorexic.

Pierre Pol: My daughter didn't eat any more and she lost her kilos. From a nice looking young girl she was like a skeleton, and she didn't realise she was a skeleton. During some years my wife and me we tried to help her in anorexia, but we didn't realise that she needed help for something much worse than anorexia.

Andrew Denton: Was she able to explain to you or even to herself why she didn't feel good?

Pierre Pol: No. And that made her anxious. Because she told us regularly she felt as somebody else inside of her was deciding. She knew that a lot of things of self-mutilation she was inflicted herself, she knew that it was bad, but she could not resist the temptation of doing it.

Andrew Denton: As she grew older, Edith's drive to self-destruction became overwhelming.

Pierre Pol: She first tried to suicide herself by cutting in her hands. She was 18 years old. At this time she sometimes told us that it was really difficult to stay alive because she didn't find a place in our life. Really quickly she told to psychologists or psychiatrists that she wanted to die. She asked me to help her die. It is really difficult to hear your own daughter asking you something like this, and she was then 18, 19 years old.

Andrew Denton: I could think of no harder thing than to be asked by your child to help them to die. What do you say in a situation like that?

Pierre Pol: Well it's really difficult because as a father you think you have to assist your children in a lot of difficult situations. I was educated in Christianity and I knew about Abraham but I was not ready to do what Abraham was asked to do with his son. I was not ready to help my daughter die.

Andrew Denton: In desperation Pierre Pol and Edith went to specialist after specialist.
Pierre Pol: A lot of psychiatrists and psychologists we met tried to catalogue her somewhere in the known psychological or mental illness, but no-one succeeded in this exercise. Then when she heard about the law in Belgium who allowed euthanasia in some specific cases, she read it and she told us, "I am eligible for euthanasia in Belgium," but most of the medical doctors who followed her didn't follow her in her question.

Andrew Denton: So did you genuinely explore with doctors whether or not Edith could undertake euthanasia?

Pierre Pol: I made a big mistake, because maybe I thought Edith was too ill to really understand what was written in the law. I had a stupid behaviour because I was full confident in the medical doctors I met. Maybe I had to study further the Belgian law about euthanasia.
Andrew Denton: So you thought it didn't apply to Edith?

Pierre Pol: It could apply completely to Edith but in a lot of cases it is difficult for some medical doctors to allow that they can't help the patient any more. Then they say it's not allowed, but legally Edith was right.

Andrew Denton: How many doctors did you and did Edith talk to about euthanasia?

Pierre Pol: Edith did something around 20 and me maybe 15.

Andrew Denton: And they all said, "No, this is not right for her"?

Pierre Pol: They all said, "No, it's not lawful".

Andrew Denton: So between you, you saw maybe 30 doctors. As this went on and on, did this make Edith more desperate?

Pierre Pol: Desperate in the sense that she spoke lesser and lesser about euthanasia, and maybe as parents we interpreted this as she was going better, but I think she didn't want to speak about euthanasia anymore because she was planning a suicide, and trying to euthanise herself.

Andrew Denton: How many years between her suicide attempt when she was 18 and when she did kill herself – how many years took place?

Pierre Pol: Eighteen. Eighteen years of heavy psychic sufferings, suicide attempts a lot, auto mutilation with razor blades, with fire, with cuttings everywhere on her body. It's difficult to understand how it is possible. She told me that when she was cutting in her flesh it helped her feeling better because her psychic suffering was that heavy that in cutting or burning her own flesh was giving her the impression she was healing from her psychic sufferings.

Andrew Denton: It is extraordinary what the human brain can do. You said she made more than one suicide attempt. Is that right?

Pierre Pol: Yes. More than one. She was really angry, because she didn't succeed. The last weeks before she succeeded in suicide herself we phoned a lot to the doctors who were following her because she was in a psychiatric institution. We told them she is not going well and she is preparing something, and she cut her throat in the psychiatric institution where she was.

Andrew Denton: Had there been a genuine conversation about euthanasia with yourselves, with the doctors, what difference do you think that might have made?

Pierre Pol: The difference I only understood it afterwards – we are convinced that Edith asked a legal question and that maybe it had been important to discuss with her about euthanasia versus suicide, instead of trying to avoid this discussion. It's really important because when you speak with psychically suffering people about their question for euthanasia, more than 50% of them choose to stay alive. They find a kind of medication that their suffering is recognised and then maybe death is not a problem anymore, because they could receive help to die. In the case of Edith, more than 10 years medication, psychiatric institutions didn't help her. Most of the doctors knew she was incurable, that medicine couldn't help her anymore, so maybe it's time now to start avoiding this kind of discussion

and to speak clearly with some patients about their suicides or their euthanasia. As a father, it's really difficult to read a police report describing what's happened to your daughter when she suicide herself. It's horrible. When I discuss with parents of people who are euthanased it seems so peaceful. Difficult to use words. It is beautiful, because they can say goodbye to each other.

Andrew Denton: For all your deep love for your daughter and care for her, is there a sense that you failed her even though you didn't know that you were failing her?

Pierre Pol: Yes. My feeling is that I failed somewhere because I cultivated my hope without understanding her despair. I thought we can solve everything in life with love or with parental care. But it is not true. There is a limit even to love and even to parental care.

Andrew Denton: Have you been able to forgive yourself?

Pierre Pol: Not every time. I sometimes still have doubts, but those doubts are especially – the way I communicated to my daughter. Maybe her sufferings were that much I didn't always spoke to her as if she was a healthy young woman, and she was indeed a healthy young woman with an illness. Her brains functioned fantastically good, she knew what was happening, she realised that with all those medicines she was only a shadow of the beautiful clever young woman she used to be. She realised that she was already dead, and whenever she asked for help for euthanasia the answer of the doctors was to condemn her to stay alive.

Andrew Denton: Do you understand why people struggle with the idea of euthanasia for people of a young age?

Pierre Pol: Yes, I understand. But the only advice I can give to those people who are hesitating – and I understand; it is really difficult – they should discuss directly with people in psychological sufferings. Not with the doctors, not with the parents of those people, but with the people in psychiatric sufferings. In Belgium every day – six suicides a day for psychiatric sufferings, and if you listen correctly to what those people are experiencing and if you communicate correctly about their dreams of suicide or euthanasia, maybe you can save more than 50% of them.

Andrew Denton: In a way no doctor ever could, Pierre Pol had described for me the true shape of the monster they were dealing with. Not depression, or psychosis, as I understood them, but something far deeper, darker, and unyielding.

Laura may only have been 24 but she, too, had been in treatment for years for extreme depression and complicated psychiatric disorders – since the age of 12 in fact. This had manifested itself in suicide attempts and other, consistent, acts of self-harm.
A few months after leaving Belgium, I found an interview with her online, conducted by a documentary maker working for *The Economist* magazine. The scars on her arms clearly visible, this is how she described her life:

Laura: I feel like there's a monster behind my ribcage constantly trying to get out. Cutting makes you think, "I can cut it down". And banging your head on the wall makes you think, "I can beat it". But even slamming and hitting won't stop it. That's the hardest, picking yourself up every time, when you know 5 minutes later it'll be back and you have to go through it all over again. That's what makes it so unbearable.

Andrew Denton: Lieve, when you talk to Laura and she expresses "This life is not for me," what do you say?

Lieve Thienpont: Well every time I see her or mail her or I hear her, we speak about life, and maybe, maybe there's more possibilities to try something more, and that's of course really my wish – that even now she can find a way out of her pain by another treatment, but at the same time I know she wants quietness or she wants the possibility to die in a good way and it's like balancing those two. I want to offer her another way to live, and at the same time I want to offer her the peace so that she can die in a soft and good way.

Andrew Denton: Is there a concern that other young people who may be struggling with depression, they learn about a case like Laura's and they begin to think towards euthanasia as a solution to their problem rather than looking elsewhere?

Lieve Thienpont: Yes, but I hope so because it's like I said before, it's an opportunity to speak about their wish to die. Some of them already wish to die when they were very young. The first suicide attempts, they were very small already, very young already.

I always saying speaking about euthanasia is not dangerous. Not to speak about it is dangerous because then they are preoccupied only with the suicide thoughts. If you can take them away, there is more space and time and energy and quietness to look at their life.
Andrew Denton: It is a paradox I had never considered before: how embracing the prospect of death can hold out, instead, the possibility of life. In her interview, Laura confirmed that the offer of a gentle death has saved her from a violent one.
Laura: Without the option of euthanasia, years of suffering would have been compounded by a gruesome and lonely death. I would have killed myself.
Andrew Denton: Even so, I wondered if Lieve in any way doubted her course.
I respect the care and thought with which you go about your work but it feels to me that you are also on a very high tightrope. Are you certain that psychiatric science knows enough to make a call on life and death?
Lieve Thienpont: It's not a science who decides, I think. It's the quality of life and the energy left that decides if people can go on or not. They decide, not the science.

Andrew Denton: Less than 2% of all deaths in Belgium are by euthanasia. In 2013 97% of those were people with terminal or chronic physical diseases; 3% were psychiatric.

Within the Belgian medical community there is ongoing debate about how best to deal with such cases. Some feel strongly that euthanasia is not appropriate. If you'd like to know more, head to the episode page at wheelercentre.com/betteroffdead.
For me, Laura's story was, by far, the most confronting thing I found on this journey. It took me a long time to understand the true nature of her unbearable suffering and even longer to appreciate how the people at ULteam were using euthanasia as a way of encouraging her to live.
You may hear what I have heard and still think that their approach is wrong. But I came away with a respect for what they're doing.
To truly seek to understand the unbearable suffering of others, to walk beside them into the darkest places searching for even a glimmer of light, and – should their suffering prove beyond endurance or treatment – to promise a loving way out, was, to me, a remarkable display of rational compassion.

I couldn't help but wonder how many people in my country, suffering in this way and desperate for relief, might have been kept alive by the same approach.
And Laura? She had nominated last August to end her life by euthanasia but, as the day approached, opted not to. She's in treatment still and – in her own words – is "holding her breath for the future".
Andrew Denton: Next episode I travel across the Atlantic to the last place I expected to be discussing assisted dying: the state of Oregon in the God-fearing US of A. Not only do they have a law to help people die, but it's the longest-running one in the world. How did something so controversial become law in such a religiously conservative country? And, 17 years later, why is there no controversy about it at all?
[SONG 'FORTY-EIGHT ANGELS' BY PAUL KELLY]

[CLOSING CREDITS]