

## **Episode 16 – Abandon Hope**

**[SUICIDE WARNING]**

**[PRAYER BELL CHIMES]**

**[ETHEREAL FEMALE VOICE]:** There is no death. There is only me, me, me who is dying.

**Andrew Denton:** My name's Andrew Denton and, you're listening to *Better Off Dead*, my search for the truth about assisted dying.

It began when I was invited to attend the HOPE anti-euthanasia convention in Adelaide, featuring speakers from around the world. Here I heard dire warnings about what was happening in Belgium, The Netherlands and Oregon where laws to help people die already exist: I heard of the vulnerable being made expendable and of people being killed without their consent. I heard of blind twins being euthanased after having to shop around for two years to find a doctor who would do it.

And I heard of a slippery slope where the number of people seeking to die was sharply on the rise.

Above all, I heard two key accusations: That the he safeguards don't work; and that the elderly and disabled were threatened. I took careful note of it all, then took off overseas to see if their warnings held true.

Now, many months later, I sat down with HOPE's director, Paul Russell, to talk through what I'd learned.

**[OPENING TITLES]**

**Andrew Denton:** We'll start with the easiest question. Can you give me your name, your age and your official position?

**Paul Russell:** My name is Paul Russell, I am 57 years old, and I am the director of an organisation called HOPE: preventing euthanasia & assisted suicide.

**Andrew Denton:** Can I just say I have extreme envy. I just heard your voice in the headphones. You have got the voice I always wanted. [Laughing]

**Paul Russell:** It happens sometimes.

**Andrew Denton:** You have got a radio voice.

**Paul Russell:** [LAUGHING] I have got a radio head too I think.

**Andrew Denton:** Paul Russell is a welcoming, avuncular, man with a ready laugh and an appetite for a fight. Formerly a senior officer for the Catholic Archdiocese of Adelaide, he quit full-time work 4 years ago to take up the battle against assisted dying.

**Andrew Denton:** On the question of euthanasia/ assisted dying, if you look at Canada, you look at the States, even New Zealand, there seems to be an increasing momentum for people to want to know more about and have more choice about what happens at the end of their life. Do you have a sense that maybe you are swimming against the tide of contemporary history?

**Paul Russell:** [Laughing] I guess that's possible. I sort of hope not obviously. Yeah, it may well be the case. But being motivated by my sense of what justice is, ultimately I am not going to throw in the towel because there is a tsunami coming. I am not going to stop advocating. That is just who I am.

**Andrew Denton:** And I should preface the conversation we are having by saying I think all the questions that you raise and that are raised by those who oppose these laws are valid questions. They should be asked and must be asked about the vulnerable, those who may be threatened. How if you have these laws do you make them safe? So I genuinely respect the conversations that you raise. My question is more about how those conversations are held.

**Paul Russell:** Mm. No, that's fair enough. I think there's sometimes frustration on the polarised nature of debate

**Andrew Denton:** At the symposium one of your guests by video link was Theo de Boer, the Dutch professor ethicist, who had resigned from the euthanasia review committee and become a critic of the system. . He talked about euthanasia becoming a default option for dying cancer patients and he particularly talked about the annual 15% rise in euthanasia deaths in the Netherlands as being very alarming. Why do you find that alarming?

**Paul Russell:** Well a number of things. Now we must recognise that the law in Belgium and the Netherlands was broadly written, and that was for people at the end of life, for whom pain management wasn't sufficient in subjective terms, that there would be a way out for them in terms of euthanasia or assisted suicide. You are really looking at a ceiling of probably somewhere in the order of 2, maybe 5% at a stretch, of people that that would have affected, so I would have thought by now we would have reached a sort of ceiling or a plateau in the numbers of deaths. Well that is clearly not the case; it is clearly still escalating.

But what that points to I think is really a sociological matter that could be used to draw a conclusion that the societies there have become very blasé about accepting this. And I think what concerns me most is the stuff that you almost can't prove, you know – how societies change, how people's views of other peoples change. Are we going to be sort of translating in some way, perhaps in some incremental way, a view of people with disabilities, people who are ill, people who are ageing, people who have all sorts of issues, who aren't perhaps contributing to society in the way the rest of us do, for example, are we going to be translating that sort of view writ large across our community in some way? And I think the figures suggest that in some way.

**Andrew Denton:** That 15% figure though when you put it in context becomes something different because it represents a population which, like ours, is getting older. The vast majority of these cases have always been and still remain cancer, heart failure, neurological, and the number is less than 4% of the people that die in the Netherlands every year. Which seems to me to be quite a long stretch from the idea that the genie is out of the bottle, that this society is somehow in freefall.

**Paul Russell:** Well you know that was Theo's call. I'm not sure I would have used that form – I can't, I'm not there. He's the one who is seeing it. I wouldn't say Theo is now a spear thrower or a banner carrier for our side of the argument – not by any stretch.

**Andrew Denton:** The interesting thing is that the Dutch themselves overwhelmingly support their own laws. I think it is 85% to 5% opposed, the medical professions are on board with it; no mainstream party has attempted to repeal or amend the laws.

**Paul Russell:** That's right. Mmm hmm.

**Andrew Denton:** They are very comfortable and confident with how their laws are operating. So when I hear suggestions, which are often made, that the Netherlands is a society which is losing it, I think that's a misrepresentation of how they themselves see what's happening.

**Paul Russell:** Well, I mean you could turn that around and say the fact they don't see there is a problem is a self-evidence of the problem. [Laughing] I mean where do you go?

**Andrew Denton:** Well that that is a little bit patronising, isn't it? I mean...

**Paul Russell:** I'm saying you could suggest it; I'm not saying you should, by any means. None of this is exact science. So there are a lot of studies that look at the figures, and I think that is a really important thing to do, and there are from time to time horror stories that come up, and it is important to explore them as well. And look, I could be accused if you looked at my blog of being polemic at times with some of the data etc. You might say well in a sense that is my job, and yes, we want to win, but at the same time you have to take the time to look at the truth of all this. And really it is not so much that there is an empirical framework to the deepest reasons of why I think the way I do; it's more what I think is an understanding of the human condition, the fact that injustices do happen, the fact that the law cannot always fix problems, nor can it contain problems, that perhaps we need to find better expression for the sense of compassion that we have. Yeah, so it is not sort of measurable in that sense.

**Andrew Denton:** In truth though, there is no law that would ever pass muster for you because you fundamentally object to the idea of there being such a law.

**Paul Russell:** No, I'm sorry that's a slight misrepresentation of my views, but you are not to know otherwise.

**Andrew Denton:** No, look, please tell me I'm wrong. Tell me the law that would pass muster for you.

**Paul Russell:** I don't think there is one. That's the point. Sometimes I have looked at bills and I have thought, 'Hey, wow, that is pretty good', but when you look at them there are some fundamental things that can't be addressed in the black letter law. My friend Craig Wallace talked about this in the Senate enquiry last year. He was saying, "Well what is terminal illness? Give me a definition of terminal illness". And his point was that many of his friends in the disability community have situations that, other than for some support or other, actually are terminal. So how do we write a framework that works?

I think also the problem is once we cross a boundary that has been in existence for many millennia, we have already got to pause and say, “Well OK, we have held the line on this for so long now, there is a reason for that”. And I think was it Chesterton who said something about before you move to knock down a fence perhaps you should ask why someone put it there in the first place. They're big questions.

**Andrew Denton:** But there is another way of looking at this, which is that all societies face the terrible reality of people that die awful deaths that are beyond the help of medical science, so the other way to look at it is: well, as a society, knowing what we know with our vast improvements in medical knowledge, is there more we can do to help these people, which is yes, you could say that is centuries of tradition that we are turning against, but societies always change. 3000 years ago Spartans were throwing babies off cliffs. As human beings grow and learn more, we also change what it is we do, based on our knowledge.

**Paul Russell:** Look, that is self-evidently obvious, but it still doesn't change the fact that it is an incredibly serious matter. You mentioned there about people we can't help. I don't think that's the case. I mean unpack what “can't help” means. We can help; we certainly can help. We can keep developing. I wonder too whether sometimes the whole process of innovation and development of society is because we are banging up against the wall and we decide how are we going to stop that? Do we knock the wall down? Or do we allow that creative tension to move us on in the fields of science?

**Andrew Denton:** Or do we create a ladder which allows some people to go over it?

**Paul Russell:** Ah, well, you go changing my metaphor. [Laughing]

**Andrew Denton:** Improving, improving your metaphor.

**Paul Russell:** [Laughing]

**Andrew Denton:** You talked before about shocking cases, individual cases. One which I know that HOPE talks about, and a lot of people talk about, is the deaf Belgian twins Marc and Eddy Verbessem. What do you know of that case?

**Paul Russell:** That's a really hard case. You know, you had the story of these two twins who had twin ailments, and a beautiful story of them having a life together. And they're going blind, you know. They were deaf and they had other difficulties, so their sight was obviously critical to them, and I have every empathy with that situation. But they looked for two years to find a doctor who would agree to euthanase them, because essentially the presenting story is that we have two people here going blind. I mean you can't – I find that – in my head I have a conflict in a sense with that because you could headline – look, I may have even done it – “Twins euthanased because they were going blind”. I mean [INDISTINCT] der! That is ridiculous! We have to accept that there was a back story and it was a very difficult back story, but at the same time it is not a terminal illness. They had other degenerative illnesses certainly.

But I struggle with this idea that you can go to a doctor –I don't know whether it was their regular doctor or whatever, and he says no, and then you say, “Well I will go and find somebody else,” and this process of taking two years. So even in that society clearly at least for whatever number of doctors they saw who said no, there was some sort of recognition

that, “No, no, no, this is not where our law is intended; this is not the solution for you,” whatever. And then they found – well they always were going to find someone who would do it. To me that is one of the problems with these laws. Having to sort of go to two doctors is not a roadblock for someone who is just simply suicidal; it’s not.

**Andrew Denton:** Can I unpack a few of the things you have said there. Not a terminal disease, but as you know, under Belgian law, that is not the criteria. It is unbearable and untreatable suffering. The second thing is this idea of doctor shopping. Their GP, the family’s GP – and the GP is always the first port of call in these cases. He said – and he swore this in an affidavit to the Canadian Supreme Court – that there was no doctor shopping. So I would be inclined to believe his version of events.

**Paul Russell:** So would I. I actually hadn’t heard that. But that was as it was reported – that they had looked for two years.

**Andrew Denton:** I think maybe you need to change the story on your website.

**Paul Russell:** [LAUGHING] Perhaps I do! You know that is a difficulty, that is a real difficulty in this stuff, and you know there are those that sort of pick at when people get things slightly wrong that that, but...

**Andrew Denton:** Well, but I raise this because I think it is important.

**Paul Russell:** Oh, it is important, but to me again, as I went back earlier, from what I saw about that story, it was an example of a problem that I perceived. It wasn’t proof. You know what I mean?

**Andrew Denton:** Yeah, but it is held up – you know that the personal stories are the most powerful ones in these arguments. I am sure you are aware that the parents and the siblings of the brothers supported this choice, which puts another complexion on it too – the compassion they showed to support what would be the hardest choice anybody could ever make.

**Paul Russell:** Agreed. Yes, no question. I definitely knew of that.

**Andrew Denton:** As research for this podcast we contacted the family of those boys and they expressed to us their great distress that anti-euthanasia coalitions, including HOPE, would be using their story as an example of a law gone wrong, and you know, you are a very decent guy, does it bother you that you are adding to their already considerable anguish by making stories like this, which you have already said you don’t know all the details, making stories like this into, if you like, a bullet to fire in the war?

**Paul Russell:** OK, that is a really good point. I certainly don’t want to add to anyone’s distress personally. It does upset me to think that I may have. I do get polemic at times. I don’t doubt that. And I think in terms of talking about life and death and justice etc I think it is quite visceral. There is a tendency to that.

I’m not justifying it. I was not aware of that. But from this distance it is hard to check. I am quite sad to hear that that is the case.

**Andrew Denton:** Let’s talk about disability. I spent some time the other day talking to Joan Hume, who is fantastic. It was really disturbing and eye-opening to me to hear the genuine

place of concern from which she comes, and which I am sure you share, which is there are attitudes expressed in this society towards disabled people which are probably, to put it mildly, dismissive of them.

**Paul Russell:** Hm. No, that's true.

**Andrew Denton:** At the symposium Nancy Elliott from New Hampshire got up and spoke about, you know, 'If you are arguing this publicly, you need to have several lines of attack, particularly if one of them gets knocked over. And she talked about disability abuse as being a particularly strong thing and to get disabled people to speak. In fact I think she used the expression, 'The disability argument is really kicking it right now!'

**Paul Russell:** [Laughing]

**Andrew Denton:** Which was a very American expression.

**Paul Russell:** I suppose it is.

**Andrew Denton:** The clear impression I got from the HOPE symposium, was that people with disability were going to be more vulnerable under these laws, and perhaps were more vulnerable under these laws in this country.

**Paul Russell:** Yep.

**Andrew Denton:** So when I went to the Netherlands, Belgium and Oregon, I went to the peak disability groups in these three countries to ask them, and I put to them in a neutral way, I said, "These are not my questions, I'm going to ask you a whole range of them – about coercion, vulnerability, about being made to feel less valuable, about there being pressure because it is more economically beneficial for the country". I asked them a suite of these questions, and unanimously they said, "No, there is no issue". I will read you a couple of the quotes.

This is Pierre Gyselinck, who is the president of the Belgian Disability Forum: "I have not and we do not have any knowledge about it" – this is vulnerability or insecurity – "But I am sure, and in my opinion and in the opinion of the BDF, we have no fear that people with disabilities are more vulnerable since the law was installed".

Illya Soffer from Ieder(in) in the Netherlands, who represent 250 disability organisations, when I asked about safeguards, she said: "I think the most important protection in this law is this issue of your own judgement. The other protective issue is there must be a case of unbearable suffering. This must be assessed by two or three doctors and also the family around and the person themselves. So I think that procedure, which is a very strict procedure, if you look in the Netherlands, I think you see more people complain on how strict the procedure is than on how coercive it might be for people who are vulnerable to these kind of practices".

And Bob Joondeph, the director of Disability Rights Oregon, said: "Since the law has been passed we have not received a complaint from anyone, other than a complaint from a person who was paralysed who was concerned that the law discriminated *against* them because the law requires a person to self-administer and they were physically incapable of doing that".

It bothers me that the impression given to the disability community here in Australia is they have something to fear, whereas the lived experience of peak disability representatives in these countries suggests quite the opposite.

**Paul Russell:** You will find – I mean a disability group is not a homogenous community by any stretch of the imagination; they are incredibly diverse. You will find, even in Britain, there are some disability activists who sort of see, “No, I don’t think there will be a problem”. All I can really say is that we don’t dismiss these concerns. Just as much as Belgium and the Netherlands are different societies, we should be striving to work hard to ensure that people with disabilities are respected, valued, an integral part of our communities in every respect.

**Andrew Denton:** I agree entirely but should you be amplifying those concerns? Which is what I think you do.

**Paul Russell:** Oh well I am interested to hear that. I am not amplifying them. I’m very conscious of the fact that disability people need to speak for themselves in the disability community. I let them speak for themselves. They are the ones saying this.

**Andrew Denton:** The information people here in Australia people are getting is a very fear inducing picture of terrible things that are going to happen to them, but in the places where these laws exist those terrible things haven’t happened.

**Paul Russell:** They are different societies. That is the only comment I can make about that, and also the fact that these people in Australia are making it in their context. They’re not talking in the Belgian context. They are saying, ‘If we brought a law in here right now, this is the way we experience life here. This is what we fear’. Now whether those fears are actually, again, empirically able to be proven or not, I don’t think it really comes into it. It’s their story! [Laughing] Leave them speak for their story.

**Andrew Denton:** The other thing I noticed Nancy talked about – and why this is relevant is she was guiding people about how to prosecute the argument in public.

**Paul Russell:** Yeah.

**Andrew Denton:** And the list of things – Another one was elder abuse. Similar thing – that the elderly in our society and in any society are vulnerable. So a very, very fair question to raise in the context of assisted dying. Probably affects them more than any group. So again I went to the peak elderly groups in these three countries to ask their view on these questions of vulnerability and coercion, and again, across the board it was, ‘We do not see any evidence of this’. In fact it was interesting, they went further. They said, ‘It is the opposite’. They said that, “This has empowered our members, and for those who face the prospect of a terrible death it has given them comfort”. So I question the assertion from someone like Nancy, who was at your symposium, that the elderly are facing abuse, when the lived experience of the people in these countries is the opposite.

**Paul Russell:** Again, I come back to you and say, look, they are different societies. I don’t know that we can compare them. Again, it is encouraging. But the point you made about sort of people feeling empowered by having this knowledge. There is truth to that; there is no question about that. But what I would question in turn is also that I think if people had a lot more understanding about their ability to exercise their autonomy in the framework of a good

care plan and with good quality palliative care, absent of euthanasia, I think there is every chance that they would find the same reassurance, and that is the problem I have with it. You know, elder abuse is a modern phenomenon that is of serious concern, and again, I tend to point to the fact that this is evidence of this concept that people are vulnerable. They *are* vulnerable, they *are* in difficult circumstances, and the connection between euthanasia and assisted suicide therefore, though not proven entirely, is definitely worth considering.

**Andrew Denton:** Definitely worth considering, but based on their words I think it is fair to argue that by their assessment it is possible to create a system where elder abuse is not an issue.

**Paul Russell:** Well, absent the human condition perhaps. I don't think you could...

**Andrew Denton:** But they are human beings.

**Paul Russell:** No, no, no. I'm just saying I don't think you can be that absolute about it.

**Andrew Denton:** No, but it is certainly possible to say that in *their* countries they were capable of doing that, by their assessment.

**Paul Russell:** No. I mean I take you at your word on that. I haven't...

**Andrew Denton:** So Paul – Aussie, Aussie, Aussie, Oi! Oi! Oi! – where is your faith in us? Why can't we do this?

**Paul Russell:** Perhaps we can. Perhaps we can. But I don't think we can fall into the trap which I think is quite utopian really, in saying that we can actually create a law that works. To think that every doctor is going to always work ethically, that there is going to be no circumstances where someone's consent to a euthanasia or request for assisted suicide isn't influenced by all sorts of sub-currents of thought, suggestion, pressure – I don't think we can do that, and again, that is the point, when you think of disability, when you think of elder abuse, where these things can occur. More than that, simple little nuances of words or thought – “Oh it's your decision, Grandma”. It sounds like a good thing just to affirm someone's autonomy and say, “It is your decision”. But what does Grandma hear? You don't know. There is a lifetime of experience in between those two persons that informs what Grandma hears when you say, “It's your decision”. So I really don't think when we are talking about difficult circumstances and interplay between all sorts of personalities, that we can actually do something in terms of a law that we can sit back and say, “That works”. I just don't think it's possible.

**Andrew Denton:** No, I think the overseas experience would disagree with that.

Can I talk about something which I think is more problematic, which is I think about clear misinformation, and it's Alex Schadenberg, who I had a long conversation with at your symposium. And I bought his book, *Exposing Vulnerable People to Euthanasia and Assisted Suicide*, which I think is still for sale on your – is it a good seller?

**Paul Russell:** It has been actually, yeah. Yeah.

**Andrew Denton:** Is it peer reviewed, do you know?

**Paul Russell:** Well what is it doing? Just citing studies that exist, which I imagine because they come from journals are themselves peer reviewed, yes.

**Andrew Denton:** That's correct. They are peer reviewed. His big claim is that this is not just his opinion but that he has gone back to the original surveys done by medical and other authorities in Belgium and the Netherlands to see what it is they're doing, and he said in this book that this is proof that no assisted dying or euthanasia law can protect vulnerable citizens. For example, he went to the *New England Journal of Medicine* 2009, an article called 'Medical End of Life Practices under the Euthanasia Law in Belgium' – it is a page-turner, let me tell you. And what it is looking at is the unreported cases of euthanasia, or those deaths occurring without explicit patient request. Now Alex's conclusion was this: "Most people who die by euthanasia without explicit request are from a different demographic group to those who request euthanasia, and that this group is more vulnerable – that is, they are elderly, often incompetent patients with cardiovascular disease or cancer, often dying in hospitals". On the face of it, that is a pretty scary conclusion. That is basically saying that there are doctors there who are killing elderly, vulnerable patients.

**Paul Russell:** Yes.

**Andrew Denton:** So when we went back to the original articles, which are peer reviewed, as you said, we found that he had omitted the conclusion of the article, which directly refutes what he is saying the article is about. And what he omitted was this: 'We found that the enactment of the Belgian euthanasia law was followed by an increase in all types of medical end of life practices with the exception of the use of lethal drugs without the patient's explicit request. No shift towards the use of life ending drugs in vulnerable patient groups was observed'. That's a pretty significant omission, wouldn't you say?

**Paul Russell:** I would have to go back and fully re-read it myself, but – no, look, I need to have a close look at that, and I will.

**Andrew Denton:** It really worries me, because we found almost half a dozen instances of this, and if I may, I will give you one other clear example, and I will take you through to my final point about it. Another article he says that he has been through is the 'Physician Assisted Deaths under the Euthanasia Law in Belgium', a population-based survey which was in the *Canadian Medical Association Journal* of 2010, peer reviewed. His conclusion was, and I quote: "that vulnerable people die by euthanasia in Belgium, and these are not being reported, making it an invisible crime". An invisible crime – that is a serious allegation. But again, he hasn't included the conclusions that the authors of this article draw, which absolutely disagree with what he is saying is their conclusion. This is what he left out: "As was shown in other research, no evidence was found to support the fear that once euthanasia is legalised the lives of elderly patients would be more likely to be ended with the assistance of a physician. Older patients thus seem not to be at higher or increasing risk of euthanasia after legalisation". I mean this is really – not to put too fine a point on it, it is intellectual dishonesty, isn't it?

**Paul Russell:** Again, I would have to go back and have a look at it. I have read those reports but it was some time ago.

**Andrew Denton:** Really what Alex is doing here by carefully picking the information he needs is trying to paint a picture of a cold and uncaring medical community committing invisible crimes. Isn't that right?

**Paul Russell:** Well, that is your opinion of it. Um...

**Andrew Denton:** It is hard to draw another conclusion.

**Paul Russell:** Well I know Alex quite well. I don't imagine he would intentionally do that at all. Um...

**Andrew Denton:** Significant omissions though. What would explain them?

**Paul Russell:** I really can't comment. I wish I could. I am slightly dumbfounded by it, I must admit. And yes, I mean you make the point I do sell the book, and so there is an association there. I really would like to have a look at that further.

**Andrew Denton:** The fact you sell the book is one thing but what is of more interest to me is that there are half a dozen endorsements from different Australian politicians, who are clearly happy to disseminate what I think most politely you could call is highly compromised research, and my question to you is: these are serious questions, they should be raised about how safe is the system, who is vulnerable and how do we safeguard them. Wouldn't it be better if the information in the public square was not muddied with this kind of distortion?

**Paul Russell:** I think the information in the public square *should* be as accurate as possible. In terms of the endorsement by a number of members of Parliament, I think it is easily understood that they read the book and thought, 'Oh OK'. And so I don't imagine they would have gone back and checked every last dot and tittle, as they say. So you know I think that is perhaps drawing a little bit of a long bow. But yes, you know, I think you are right

**Andrew Denton:** Let's finish on probably the most difficult area of all with this, because it is such a grey area. What is called the LAWER cases – life-ending acts without explicit request, which is where they look at the clinical practice of doctors dealing with patients in their last 24 or 48 hours of their lives. Now, I am assuming you are aware that there was a study published in the *Canadian Medical Association Journal* last year which revisited those something like 1000 cases that have become so controversial. Because I know that, as HOPE puts it, and as I think Schadenberg also puts it, that these were undeclared euthanasia deaths. They were not reported. Is that right?

**Paul Russell:** It depends on which study you were talking about. There were a number, there were some that went back to the death certificates and...

**Andrew Denton:** The number that is generally thrown around is about 1000 cases, which is a lot.

**Paul Russell:** I guess it is quite significant, yeah.

**Andrew Denton:** Of unreported deaths. – so they revisited it all to try and examine to what extent they truly did represent the non-voluntary termination of life, and the report found that while doctors reported the measures they took as life-ending acts without explicit request,

they perceived their actions in terms of symptom treatment; they did not classify their acts as euthanasia. Does that make sense to you?

**Paul Russell:** Yeah, it does. There were some – I think it was a study, again going back from death certificates, on the incidence of unreported deaths in I think it was the Netherlands, where they sort of looked at them and said, “OK, some of these clearly the doctors didn't think they were euthanasia but for some reason the researchers did”. There were some where there was some confusion about it. There were some where it had been clear that people had earlier identified that they would want to be euthanased. So it is not a category – you can't turn around and say, “Well, you know, there is 1000 murders for you!” You just can't do that. But when you consider the fact that consent is one of the hallmarks of both Belgian and the Dutch legislation, I mean evidence of it is an important factor.

**Andrew Denton:** I agree, and when I first read this I was really confronted, and like you, and like I think any reasonable person, I went, “What the hell? How could that be?” But as I have looked more closely at the studies, what it is describing is doctors increasing combinations of drugs, in particular opiates, which aren't a euthanasia drug, in response to pain and the very distressing symptoms of people who are dying, and they didn't have the explicit request of the patients because they are in the last hours of their life, at most the last 48 hours – in fact almost 60% of them had had a conversation prior to that. But that this was a compassionate and decent act of medical care at the end of life, the kind of act which happens in palliative care units around the world and in Australia on a weekly basis. Isn't that right?

**Paul Russell:** In terms of opioid use, yes, that is exactly right. They can't be classified as euthanasia in those cases, so life-ending without consent – I mean someone has determined that the life was ended by that action. In terms of double effect principle, if the intention is to relieve pain, to relieve symptoms, and a known side-effect is the possibility of hastening death, that is not an unethical act. It is not euthanasia.

**Andrew Denton:** No, that is correct. And what they found with that survey last year, when they went back to it, is that almost 90% of the doctors said that that was their primary intention. So it was indistinguishable really from what is accepted, and I believe by HOPE and others as supported practice in palliative care.

**Paul Russell:** It is a supported practice in palliative care. I mean there has been raised at some point in time, “Oh well, you can't know what a doctor's intention is”. Well, you know, I think you can measure it in many, many ways. Certainly the fact that you mentioned that it was by use of opioids tends to suggest that it wasn't – that those cases weren't euthanasia cases, should never have been reported as euthanasia cases and were in fact good medical ethics. It tends to suggest that. Because as Dr Paul Dunn says, a palliative care specialist, and others, when you are on an opioid regime for pain management, you can't just simply sort of up the dose with the deliberate intention of killing anyone anyway. Because you have a tolerance in your system to it, it is almost impossible, and it would be clearly discoverable on the medical charts that you brought in a semi-trailer load of opioids to do it. That doesn't work.

**Andrew Denton:** And that is an interesting point. You know, everyone in the medical profession, unless they are being ignorant or in denial, knows that patients are being hastened, their deaths are being hastened around Australia in different circumstances quite commonly. It is an open secret.

**Paul Russell:** No, I don't think it is. I don't think they are being hastened at all.

**Andrew Denton:** I have on the record, doctors – including a senior palliative care physician – talking openly about hastening death and also talking about that they know that this happens within the medical community.

**Paul Russell:** Are you talking about cases where they deliberately...

**Andrew Denton:** Yeah, knowingly hasten death.

**Paul Russell:** No, there is a difference between knowingly and deliberately.

**Andrew Denton:** Mm hmm. Same thing.

**Paul Russell:** No, it's not the same thing.

**Andrew Denton:** No, no, no. As in, they knew what they were doing and they knew why they were doing it.

**Paul Russell:** It's still not – was their intention to kill the person?

**Andrew Denton:** Yes, yes, their intention was to hasten their death.

**Paul Russell:** So their intention was to kill.

**Andrew Denton:** Their intention was to hasten their death, yes.

**Paul Russell:** Come back again – their intention was to kill?

**Andrew Denton:** Ah, I am always interested in the use of that word “kill”. As one palliative care physician at St Vincent’s said to me, “It is murder”. And I said, “But you are an intelligent man, surely you see that there is a significant difference between an aggressive and unwanted act and a sincerely requested compassionate act”. He said, “Nope!”

**Paul Russell:** Again, it goes back to intention. Was the intention to kill?

**Andrew Denton:** No, the intention was to end that person’s suffering, and as palliative care themselves acknowledge, there is some suffering that can ultimately only be alleviated by the death.

**Paul Russell:** Again, we are talking about – you said the intention was to end their suffering, yes? That is not the intention to kill.

**Andrew Denton:** I would suggest you are splitting hairs here.

**Paul Russell:** No, I am not. It is a well acknowledged moral distinction and ethical distinction.

**Andrew Denton:** And what sits on the other line of that ethical distinction, as I have discovered, because it is very strong within palliative care, is a whole group of patients screaming for more pain relief who are refused it. And that to me is a real problem.

**Paul Russell:** They should not be being refused pain relief.

**Andrew Denton:** Look, their own survey of the 106 palliative care units in Australia last year showed that 22% of their patients died in moderate to severe pain, so by their own admission they simply can't control all pain.

**Paul Russell:** Look that makes sense that they would say there were some cases, because if they were to say, "We can fix it all, you do not have to worry at all," they are going to open themselves up to some pretty massive lawsuits probably.

But yes, I agree. We cannot always help all people. I mean I can't sit here and say, 'Don't worry; your end is going to be just fine'. I don't know that. I can't confirm that. But I do know there are people who believe they have the expertise and have used their expertise over many years that have achieved that. What we can see clearly, however, is there is a need for improvement in that area.

**Andrew Denton:** I don't think anybody is arguing that there should be less resources put into palliative care or that it doesn't serve a valuable service or that the people in it aren't deeply impressive and doing very hard things. But equally within palliative care themselves there is the reality that just as people live in complicated ways, they die in complicated ways.

**Paul Russell:** Oh indeed.

**Andrew Denton:** And it is simply not possible to manage all peoples' deaths in a way which everybody would like, and it is that small group – and it is always a small group – that avail themselves of these laws, that small group who these laws are designed to help. What I see is there is a compassionate and rational way to do this.

**Paul Russell:** I see that absolutely we should be compassionate. I think we can do much better. There are some people for whom the slightest bit of pain is difficult; there are some who can manage amazing amounts. I've seen that variation. So we are in many respects talking about a subjective thing. We are in terms of the law anyway. We are talking about unbearable suffering. That is totally subjective. But I just don't see how a blanket law that puts other people at risk can be justified by that. I think what that demands of us – we can't just say, "Oh well we feel really sorry for that little group but we need to draw this line". We can't do that. It can never be that. But I think we do actively cause ourselves a problem when we identify that problem and then jump to this solution, because I think there are other solutions. I am certain there are other solutions.

**Andrew Denton:** Whereas I guess I would put it the other way, which is I think it is demonstrable you can create a system which gives sufficient protection to those you are worried about. That to me is a far more moral thing to do than to say, "No, it is too hard, it can't be done," and to turn your back on the people we *know* are suffering in horrible ways in our country every week.

**Paul Russell:** Yeah, well you have just made the juxtaposition with something I fundamentally don't agree with anyway, and that is just leaving them there and saying we can't do anything. No!

**Andrew Denton:** But it's not that people don't want to do anything. As we have just agreed, there is a point at which medical science, there are groups of people – it is not one particular disease, although if you were to name one, where they all say, “It is beyond us,” it is motor neurone disease – but where groups of people can't be helped because people die differently.

**Paul Russell:** You're saying can't be helped. I don't agree that they can't be, so that is where I think there is a divergence of paths, but look, in terms of what do we actually create when we create a law on euthanasia, my argument is this: that we create a right. It is called the right to die after all, and we are saying at the beginning we are going to have it and it is going to be for people with six months or less to live etc etc etc, and we are going to say there is the safeguards package, let's go! What happens, I believe naturally, is that people will see that for what it is. They have created a right and then they have limited it to a small group. And so what we will see is people outside of that group ultimately say, “I want my right too”. And they would have every reason to ask that. They can say, “Oh it is discriminatory. All right I have got 12 months to live but I really am suffering. I want to go now. Why are you making me wait six months?” I think that is inexorable, and whether we talk about a slippery slope, you know people will say, “Oh the law in Oregon never changed”. Well you know it was only last year that an MP there was trying to push it out to 12 months, from 6 months.

**Andrew Denton:** You would have to work very, very hard, Paul, to find problems with the Oregon legislation – a pitifully small number of people within very narrow definitions, and that society may look at that and go, “Yeah, we realise now this has worked and we realise there is a whole group of people who are suffering needlessly from 12 months rather than 6 months”. They may make that decision in an intelligent and informed way based on their 17 years of experience. When you talk about rights, there was a beautiful response from Eric Willeke, from the Royal Dutch Medical Society, their policy officer, and I asked him about this right to die and he said, “There is no right to die. Death is just a fact at the end of life”. He said, “What there is, is a right to *request* help to die, but that is the only right”.

**Paul Russell:** Oh OK! Well that is an interesting way of putting it. Yes, but this whole question of choice comes in then, doesn't it? You know so that is the point where I have made a conscious decision to request it and then it is up to a doctor or a number of doctors to agree, and again we come back to this question about what that does, and we can reflect this back into the disability community again, when someone, effectively those doctors, is saying, “Well, OK, you have made this request, you have said your life is unbearable, you don't want to go on. We agree with you”. To me there is a little difficulty there that some people, the people in the disability community I know, recognise as being a key point that someone else is also agreeing your life is not worth living. That is different from agreeing that you're in pain, it is different from agreeing that you are in difficulty. It's gone beyond that. It's saying – it's subtly perhaps even saying, “If I was like that, I wouldn't want to live; if I was like you, I wouldn't want to live”. And that is the kind of rhetoric that people in the disability community say they hear intrinsically on a regular basis.

**Andrew Denton:** As I listened to Paul returning to one of HOPE's favourite themes – that a law which is entirely voluntary, and which can only be accessed by people with untreatable

suffering, would somehow be used to persuade disabled people to their deaths – I was suddenly reminded of an old cartoon from the 60s.

Do you remember *Milton the Monster*? Do you remember that cartoon?

**Paul Russell:** Vaguely, vaguely.

**Andrew Denton:** It's this ridiculous cartoon where he creates a monster, but in it he puts in – it's like six drops of terror...

**Paul Russell:** Essence of terror, five drops of sinister sauce.

**Andrew Denton:** Five drops. And that is kind of how a lot of what I think...

**Paul Russell:** [Laughing] It's all coming back to me.

**Andrew Denton:** Very good! that's what a lot of the arguments I see, with respect, HOPE puts – that seems to be a lot of what it is about, which is if we just put in the drops of terror, the sinister sauce and we can really scare ourselves about it. And looking at the Schadenberg examples...

**Paul Russell:** Yeah, yeah, OK.

**Andrew Denton:** I think there is a lot of sinister sauce in there.

**Paul Russell:** OK, fine, well I appreciate that. It's sort of an outsider looking in perhaps. That's fair – I would say it is not fair comment but I'll...

**Andrew Denton:** And on one level it doesn't surprise me because if I am trying to win a fight, these are probably tactics I'm going to employ.

**Paul Russell:** Well tactics, tactics, talking points – we all do it. Everybody who is pushing an issue or defending against an issue does exactly that. That is part of, I suppose, the game of it. Because it is a moral and ethical thing and because it is for me [INDISTINCT] justice, sometimes it touches deeper places. And sometimes it *is* about winning, sometimes it is.

**[MILTON THE MONSTER OPENING]**

**[NARRATOR]:** On top of old Horror Hill in a secret laboratory, Professor Weirdo and Count Kook were in their monstrous glory.

**[Professor Weirdo sings]:** Six drops of the essence of terror, Five drops of sinister sauce....

**Andrew Denton:** I'm indebted to Paul and the speakers at the HOPE convention for their invitation. It was their warnings about the many failings, even crimes, to be found in Belgium, the Netherlands, and Oregon that guided my inquiries. I used their accusations as my framework for questioning how these laws work overseas and, repeatedly, I found those accusations wanting.

It's worth noting that, at the time of recording this podcast, four months after my conversation with Paul, Alex Schadenberg's book was still for sale through the HOPE website.

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

Andrew Denton: If you'd like to know more, head to the episode page at: [wheelercentre.com/betteroffdead](http://wheelercentre.com/betteroffdead).

In our final episode, I'm going to lay out what I think a law for assisted dying in Australia should look like.

And we'll hear from the one group of medical professionals who officially support such a law – those who see the suffering of patients daily and up close, Australia's nurses.

**[CLOSING CREDITS]**