

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 18 November 2015

Members

Mr Edward O’Donohue — Chair

Ms Nina Springle — Deputy Chair

Ms Margaret Fitzherbert

Mr Cesar Melhem

Mr Daniel Mulino

Ms Fiona Patten

Mrs Inga Peulich

Ms Jaclyn Symes

Participating Members

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Staff

Secretary: Ms Lilian Topic

Witness

Mr Andrew Denton.

The CHAIR — I would now like to welcome Mr Andrew Denton, who is appearing in a personal capacity. Before I invite you to make some opening remarks, I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded. You will be provided with a proof version of the transcript in the next week or so, and transcripts will ultimately be made public and posted on the committee's website.

The secretariat has circulated to us your recent media appearances so we are familiar with those. They have given us some good background on your personal experiences that have led you to go down this road. I invite you, Mr Denton, to make some opening remarks.

Mr DENTON — Thank you very much. First of all, because anything I say is protected, there are just a few people I would like to tee off against! No. I have never had this opportunity before.

The CHAIR — But we are recorded.

Mr DENTON — Dammit. Can I say first of all, seriously, that I think it is just tremendous that the inquiry has shown such vigour and such intellectual energy in pursuing this issue. I really commend that, and I am so glad that so much of this is on the public record — in fact all of it.

To briefly explain, almost a year ago now of my own volition and in my own time I started to explore this issue closely. I put up my hand to give the Di Gribble Argument at the Wheeler Centre on the issue of assisted dying. It was my feeling that there was an argument to be made for it, but I did not want to do this without having thoroughly researched it. So I took myself around Australia and to Belgium, the Netherlands, and Oregon twice, and have attempted to speak to as many people as I could on all sides of this argument at length. These interviews are being compiled right now into a very long — possibly too long — podcast series, which will be released in January.

There is an awful lot I could talk to and about, but let me summarise where I am at this way. I started at an anti-euthanasia convention and I took very, very careful note of the arguments against, most of which I am sure you have heard and perhaps many times over. I took that as my yardstick as I travelled around. I took their questions and their allegations as my way in to these places I visited to find out where the truth lay. I would have to say that repeatedly and consistently what I discovered is that the arguments of what I will refer to generally as 'the opponents' were exaggerated, distorted, discredited and conflated.

Amongst the things which I have heard trotted out endlessly, and most recently again on *Q&A*, on which I appeared last week, where a member of the audience read out to me a statistic from the peer-reviewed internet of 500 dead babies in the Netherlands, which if you check online from *The Conversation*, who have fact checked it, it is of course not true. I heard about elder abuse or, as Sydney Archbishop Fisher put it, putting granny out of misery. I heard about disability abuse. I heard about killing babies, suicide contagion and manslaughter and murder of people wholesale in the Netherlands and Belgium.

Not only were these largely unsubstantiated accusations, but they do not hold up to the light. There is no credible evidence to support them and indeed a great deal of evidence to refute them. So I came to the conclusion after many months of this that the opponents do not bring good faith to this conversation. They are not actually prepared to engage in these issues in a provably factual way, and I think that is very important when we discuss this question because it seems to me that too often the argument in this country has been derailed by those arguments, and I am very, very glad that there is a committee which is now holding them up to the light.

It is of unfortunate note to me that one of the pieces of evidence I took with me from this convention was a book by a Canadian called Alex Schadenberg, which detailed, supposedly, using evidence from Belgium and the Netherlands, why there had been murder and manslaughter by the doctors there. These were the very words used to me — murder and manslaughter. On analysis of those, with help from the dean of law at the Tasmanian university, Margaret Otlowski, it turned out that the research documents that he had gone to in Belgium and the Netherlands, while genuine, not only had he cherry picked the evidence, which is no great surprise, but he had very deliberately left out their conclusions, which were the direct opposite of what he said they were saying. Why this is relevant to this inquiry is that the foreword for that book was written by former federal minister Kevin Andrews and it is endorsed by several leading Australian politicians in different states.

I think it is important to note this because this is how this kind of misinformation ends up on the public record in public debate here. I will contest it and I would urge you to contest it wherever you find it, because I think it has poisoned the conversation here. I would like to think that now, with this inquiry, we are moving beyond that stage.

Having said that, I do think that the opponents ask the right questions, and the questions are these: who are the vulnerable, how do we protect them, are the laws as they stand overseas — are the safeguards — adequate in doing so? They are the right questions, and I believe they have been thoroughly and effectively answered by voluminous research and experience from overseas — in the Netherlands, Belgium and Oregon. This is substantiated by the most detailed inquiry ever done into this issue by Canadian judge Lynn Smith from British Columbia, supported unanimously by the Canadian Supreme Court, inquiring into this very question — assisted dying: is there a slippery slope, can safeguards be created, do they work? Having taken evidence from around the world — the most exhaustive inquiry ever held, for and against — she found that there was no credible evidence for a slippery slope. More to the point, she said there is very strong evidence that safeguards can be created and do work.

In Australia, as I have come back from what I have learnt overseas and as I have spoken to many people in the medical profession — and in particular since I made the speech at the Wheeler Centre and appeared on *Q&A* — I have been struck by an extraordinary lack of knowledge within the Australian medical community about what happens overseas and how these laws work. A close study of the way it works — forget laws; the practical way it works — will explain to you why these systems are so well thought through and why they work in a safe way.

Let us take the example of somebody who has unbearable and untreatable suffering, which is the definition used in the Netherlands and Belgium. They go to their local GP, and they say, 'My suffering is unbearable and untreatable'. This is not a case of, 'Oh, well, that's terrible. We'll give you a quick examination, and then let's see if we can't recommend you for euthanasia'.

The first reaction of doctors consistently in these places where these laws exist when faced with a request for euthanasia is no. Doctors are inherently conservative. In the case of the Netherlands for instance, the system allows 12 years jail if you do not follow the due care criteria, which in the Netherlands I would hasten to add were actually developed by doctors, just as in Belgium their system came out of their palliative care. So you go to a doctor who is inherently conservative, who is well aware of the penalties that exist and who also knows that his work is going to be overseen by another doctor. The request comes to this doctor, 'I'm in unbearable, untreatable suffering'; 'Well, why? Why are you in this kind of suffering? What is the problem? What exactly is your problem?'. Automatically this starts to weed out those people who we are consistently told are being coerced, because an experienced doctor — and usually it is the GP — does not take very long to discover if a request is legitimate or not. This is what they do for a living. They know what symptoms are, they know what illness is and they know what the medical literature is. When somebody fronts up to them who might be being, as we are constantly told, encouraged by their children because they want to get the inheritance, that is not going to pass muster.

But let us assume, even after this conversation — even after the doctor who is obliged to discuss with the patient all possible alternatives, who is obliged to look under law at what alternative treatments are — that somehow or other this mythical person gets through that first doctor and then has to go to a second independent doctor, who in the case of the Netherlands in particular, and also in Belgium, is especially trained not just to look at the question of euthanasia but to make sure that that first doctor has followed the due care criteria. They then have to go through that whole conversation again, and they have to prove — as does the first doctor have to prove to the second doctor — that there is unbearable and untreatable suffering. So ask yourself the question: within this system, how likely is it that somebody who is being invisibly coerced by someone else is going to get through those two safeguards?

Let us assume — because all systems are open to abuse; there is no perfect law and there is no perfect system — that the worst thing happens and somehow or other these two doctors make a decision to euthanase a person who may not have fallen under the due care criteria. Two questions. First of all, why did that person in the first place come and say, 'My suffering is unbearable and untreatable'? It is a very difficult question for us to answer, because we are not that person, but let us assume that did happen and the worst happened. That doctor's work then goes to a euthanasia review committee. In the Netherlands, for example, it is staffed by a doctor, an ethicist and a lawyer, and they go through all cases — every single case.

Most cases — 90 per cent of cases — are what you would call straightforward. They are cancer, they are heart failure, they are neurological disorders. They are people who have not chosen to die; they are people who are dying and who are seeking a choice about how it happens. But there are other cases which may be on the fringes of this and which the euthanasia review committee wants to look at because they are more complex cases, such as early stage dementia. They will look at these very closely, and if they have questions about how it is done — about the speed with which it was done, about whether or not in fact all alternatives were looked at — they will bring that doctor before them.

Some cases have been recommended to the prosecutor — which is not a medical decision; it then becomes a legal decision — because they were unhappy about how it was done. It is a very, very, very small number of cases. Up until about three weeks ago, in Belgium, the Netherlands and Oregon — in over a decade of operation — there had not been a single case prosecuted. There is now one happening in Belgium, and I would argue this is an example of the strength of that system and not the weakness of it; it is exactly as it should work.

This is what Australian doctors, as I have discovered, simply have not focused on, which is how it actually works, which is why I continue to hear what I would consider to be fairly lame bleatings of, ‘But what if this happens?’ or ‘What if that happens?’. They have not educated themselves. I find this problematic. I think it lies very much and is sheeted very much at the leadership of our medical bodies — the AMA and Palliative Care Australia — who consistently, from my observation and experience, have declined to engage in this issue.

I will make an exception. I know that the AMA right now are seeking input from their membership on this very issue, and I am very pleased to have discovered that they have actually conferred with the leadership of the Canadian Medical Association, who by stark comparison addressing this very same issue held town hall meetings between doctors and patients, invited doctors organisations from overseas where these laws existed to speak to them so they could find out from their fellow doctors how it worked and what it meant for them professionally and what it meant for their patients, held open debate — not this closed thing that the AMA is doing. We do not even know the question they are asking, they will not hold a plebiscite of their members, and they will not tell us what they are talking about, so that in the end it will be very easy for them to release results which suit their view of the world. Who knows?

But in Canada, having had this long public and open consultation, they then held a debate and — surprise, surprise — not unlike Oregon, doctors have split down the middle, because it is true: there are doctors who morally object to this, there are doctors who ethically object to it and there are doctors for whom it is simply not right, just as there are doctors who feel very strongly that it is part of medical care and it is wrong to turn away from harm rather than to hide behind the mantra ‘Do no harm’. So in Canada this is what they did, and in the end, having realised that their vote was split down the middle, 91 per cent of their membership voted in favour of the motion that it should be up to a doctor’s conscience how he chooses to act on this issue. The Canadian Medical Association took a neutral position on this. This is very important, because in the countries where this law has been passed it has been because the medical professional either has initiated it and strongly supported it or has taken a neutral position. I think there is a genuine question in this country, because polls show that doctors that support it are slightly above 50 per cent — probably reflecting what you would see in a place like Canada or Oregon — but their leadership is adamantly against it.

I think it is a real question as to how we get a proper conversation going amongst Australian doctors, because research has shown that where these laws exist, three important things happen for doctors — putting aside what patients need. One is, the doctor-patient relationship is improved. Why? Because it is possible to have an honest and open conversation about end-of-life issues. The *Herald Sun* earlier this year published a survey of 1500 Australian doctors, which showed that 80 per cent of them had never discussed end-of-life care with their patients. Secondly, it affords doctors protection under the law. If they follow the due care criteria or the laws, then if they assist someone to die, they will not be prosecuted. In this country, as you would know very well, right now doctors do not have that protection, and so we have what the *Economist* put beautifully, a ‘wink and nod’ approach to death. I know the testimonies you have heard from many, many families, including one family I spent a lot of time with, the Godbold family, and you know what the human cost of that ‘wink and nod’ is. Thirdly, and this is something which I find intriguingly is consistently ignored or skipped over by Palliative Care Australia and Palliative Care Victoria in their submission to this inquiry, all research shows that in these places — the Netherlands, Belgium and Oregon — where these laws have been introduced, the funding to and the standard of palliative care services has increased markedly, against all predictions but without any shadow of a doubt.

So to me the question in this country is no longer, 'Ooh, what could go wrong?'. We know enough from overseas now to know that the safeguards work. The question is not 'What should we do?' but 'How can we not do something?'.

I am delighted to appear here today and to answer any questions you have, but I feel that it is very hard to put a figure around this. I have tried — I have done a lot of research to get a sense of how big is the problem in this country — and in the end I can only go on a rule of thumb, which is this. If you draw a line between the number of people in the Netherlands who use this law, which is a very small 4 per cent of all the people who die there, and in Belgium, which is a very small 2 per cent of people who die there, based on the category of intolerable and unbearable suffering, let us say it is 3 per cent of all the people who die in Australia who would fall under this law. Well, 144 000 people die here every year; that is over 3000 people in this country who would avail themselves of this law, which is way more than our national road toll — on which we spend billions, which we understand is the national tragedy and which we understand leaves deep scars in our community.

This is not something — and I find it increasingly vexing and I must say distressing when I see doctors continue to minimise it — that should be minimised; this is something we should no longer be turning away from, and I am, as I said, very, very pleased to be here to talk about it. As you can see, I am passionate about it, and I have said all I have got to say — and now I am going to go! Goodbye!

The CHAIR — Mr Denton, thank you very much for that opening submission. If I can just make an observation first, I draw your attention to the doctors for choice, I think the organisation is, who appeared before us and gave evidence. I think they believe it is approximately 50 per cent of doctors, which is similar to what you are suggesting for Canada. Given your examination of the different jurisdictions that have legislated, have you got a preferred model for Australia or Victoria?

Mr DENTON — I think we are very fortunate because we have all this example and scholarship to draw on now, and my preferred model is actually a mixture of the two. I think from Oregon we should take the idea of voluntary assisted dying, whereby you are prescribed medication — once you pass all the criteria — and you, and you alone, can take that medication. I will give one exception to that, and I will come back to it in a minute. This to me is the ultimate — ultimate — final safeguard. One of the most surprising things I discovered was that in Oregon 30 per cent of people who are given the medication choose not to take it. When Palliative Care talks in slightly platitudinous tones about palliation, as though only they can offer it, why do only 70 per cent of people in Oregon take the medication? Because the simple act of having it is palliation in itself — conveniently skipped over.

So I believe that being given a medication that you and only you can take is the ultimate safeguard and the ultimate act of voluntariness, which is terribly important in this issue, because — I hear it said over and over again — the expression 'killing' is used, and I strongly object to that on many grounds. When people say 'killing' not only do they wish us to look away from those who are seeking help but they completely skip over voluntariness. The exception is — and you know this story — the example of Ray Godbold, the palliative care nurse who died of oesophageal cancer and who, despite having Nembutal, as happens too often, reached a point medically in his last 48 hours where he could not swallow, and he died a bad death. In that instance I believe either a doctor should be empowered to give an injection or a driver should be created, an intravenous driver, where the patient or a designated member of their family can do it for them, as witness.

That is what I think we should take from Oregon. However, and I thought about this long and hard — and I would have to say the evidence of Coroner Olle to this inquiry ultimately persuaded me to this — I do not think there is any other acceptable entry point to this other than the European definition of 'unbearable and untreatable suffering'. I have spent time with people with multiple sclerosis and people with motor neurone disease — people with long-term diseases — who would not fall into the Oregon definition of having a terminal illness and six months or less to live. I realise that politically it is a harder thing to sell in this country, that broader definition, but I listened to Coroner Olle's evidence here, which was corroborated to me by Coroner Mark Johns in South Australia, who, though he did not give me the same sort of detail as Coroner Olle gave you, absolutely — and he wanted this on the record — said the same story, which is: we have a serious issue here with rational elderly suicides, and they are violent and they are ugly, and the public need to know about this.

As I read Coroner Olle's evidence and I read about a 92-year-old woman with chronic arthritis who had cut her wrists, I know what this evidence meant in this inquiry. I put that together with evidence myself and my

producer, Bronwen Reid, had discovered from the national coronial investigation service, which showed that every week in Australia two people over the age of 80 are killing themselves and the most common method of killing is hanging. Would I suggest that all of those people have died for reasons that would apply under this law? No. But I think based on Coroner Olle's and Coroner Johns's evidence, it is fair to assume that many of them are in that situation.

As I look at those people — beyond the boundless testimony you would have heard from the critically and chronically ill, beyond that small percentage that we know even by their admission palliative care cannot help — I ask myself, 'How can we turn away from them?'. There is no answer other than, 'We can't'.

Mr MELHEM — What I understand you are saying is about someone basically about to die with a chronic disease. Using the model you talked about, would you extend that to mental illness — for example, a 30-year-old, physically healthy, all the plumbing is good, but there is that mental illness? Would we go that far, or would you suggest that we should consider that?

Mr DENTON — Yes, I would, and I came to this after a lot of consideration. Most of my time in Belgium was spent on this very issue. Initially I found it extremely confronting, because I did not understand then what I understand now, which is that psychiatric suffering — long-term what they call therapy-resistant psychiatric pain — can be equal to or in excess of any known physical pain.

This was made clearest to me by one of the most remarkable conversations I have had in my career, with a man called Pierre Pol in Belgium. It is probably the bravest thing I have heard a man say. I sat in his front room — in this quiet, quiet room — as he told me the story of his daughter Idit, who from the age of 17 exhibited mental illness, initially bulimia but it became far more severe. She began cutting and burning herself, she was institutionalised, she saw psychiatrist after psychiatrist, she self-harmed on a severe level, she tried to kill herself twice, she was institutionalised further. She begged — she went to doctors; her father took her to doctors — under their laws to be euthanased, and the doctors consistently said no. At the age of 31, having suffered like this for 14 years, somehow or other in a lockup psychiatric institution, Idit managed to cut her own throat and finally kill herself. Her father — and you can imagine what this is for any parent to say — said to me, 'We were wrong, we were wrong. I thought love could fix everything. I realise now that my daughter couldn't be helped and in doing what we did we forced her to that end'.

What I came to understand — and I could talk about this at greater length, but I realise there are other things to cover — is that this is a very difficult area. What I saw in Belgium and the Netherlands is that it is a very, very small percentage of a very small percentage. It is approached with extreme care and open debate within their community. I spoke to psychiatrists who expressed reservations about it. I spoke to one of Belgium's leading psychiatrists called Dirk de Wachter, who said, 'I'm not sure I support this, but I myself have approved two'. Even those who have questions, they acknowledge that there are people with psychiatric illnesses who it is beyond known psychiatric science to help. So, yes, I do support it. It is very challenging. It has to be done very carefully.

To finish off, I discovered a paradox with it, and the paradox is this: while it sounds like, as I describe it, this is helping people to die — and I sat with a woman who is living proof of this; I will not go through her story, but it will certainly be in the podcast if you want to hear it — by throwing a security net, if you like, around these people, because remember somebody fronts up and says 'I have a psychiatric illness; I want to die', that is when all the alarm bells go off, they seriously gather around this because nobody wants to make a quick decision, and what they have discovered is that very often they are able to help these people, get them appropriate treatment. You referred to a 30-year-old; you may be referring in fact to the 24-year-old girl known as Laura in Belgium, a case *The Economist* has covered. For two years they have been working with Laura now, and they are working with her — because I have spoken to the people treating her — to keep her alive. Everything they are doing is to try to keep her alive. My question is: had that not been there, with the kind of suffering she has been in — she has been in treatment since she was seven, I believe — would she actually be alive today?

I came away thinking this is very hard — this is the hardest of the hard, in fact — but what I saw was a rational compassion applied to problems which we face here, and for those same people here we cannot have that conversation.

Mr MELHEM — Based on that, the whole thing is about people saying, 'Euthanasia — we're killing people, and that is sort of scary'. From what you are saying and from what I have read so far the people likely to

use that or exercise that option are an absolute minimum. Is it important to shift the debate from just the headlines, 'Euthanasia' and 'Assisted death' to the real issue of how we can assist people to have a good death?

Mr DENTON — Very much so, and I think that what has been looked away from consistently in these conversations is: who is actually suffering, why would we have these laws? You would now know way better than I who is suffering out there and the ways in which they suffer. That to me is the question. It is demonstrably possible to create laws that protect the many but which help the few — the few who desperately want our help. To me the question is the other way round: how can we keep turning away from these people? These are terrible things that are happening in our community. So I believe there is a great charge upon this committee and this Parliament and this community to find a way based on the now voluminous knowledge from overseas to do this effectively and safely.

The headlines, if you like — the horror headlines — have been very effective, but they do not speak to what is happening overseas. It is not inappropriate to talk about psychiatric or dementia, but let us never forget that 90 per cent of these people are dying already. They are not asking to die; death has chosen them. They are asking for a choice about how they may die, and that is always skipped over by the opponents of this question.

Ms SPRINGLE — My question turns to I guess thinking about the potential of legislation change. We have heard from hundreds of people about the different aspects of what that should look like and what the repercussions of that are and what have you, but what does seem to be a theme through all of that is that it is not just about legislation, it is about culture. There are varying different responses to that, I suppose. I would like to hear from you what you think perhaps the nuance of our culture could mean for potential legislation change and how that differs from overseas but also how we could start to change the culture around dying and death and those conversations and how this might work, because it is going to be more than just laws.

Mr DENTON — Yes, that is a very good point. I have wondered about this a lot. It is quite possible to go, 'Belgium and the Netherlands, they're not like us. They're a bit out there', but then you have to go, 'That doesn't really explain Oregon or Vermont or even California, or Canada, much closer to us in culture, if you like, and style and traditions'. I think the best way to answer this is to go to the final thing you were saying there about end-of-life care. It has been enlightening and surprising and not a happy experience to discover how poor the conversation about end-of-life care is in this country generally and within the medical community in particular.

I go back to what I said before: if you want to talk about culture and what it has meant in these places where this conversation is now possible to have, it has changed the culture. The things they said would happen, which is that these would become societies which were somehow horribly transformed into death cults, demonstrably have not happened. But what has happened is that it is now possible for doctors and patients to have honest conversations. More than that it would be difficult to speculate. I think there will always be groups, and they have a right to that moral view, who will find this a traducing of their view of the universe, just as there will always be strongly humanist groups that feel there is a right to die. I very much like Eric van Wijlick from the Royal Dutch Medical Association. When I asked about the right to die, he said, 'There is no right to die. Death is not a right; it is just a fact at the end of life'. I thought that was a very good way of looking at it.

The truth is — and spoiler alert for your committee — we are all going to die. People are well aware this is happening. I think it is just another one of those emotional furrphies thrown up: 'If we legalise this, people are going to want to somehow or other be encouraged to this'. Of the many wonderful things I was told, it is interesting to note, and I would like to put it on the record, that there is a fascinating little universe of fear out there. Little institutes and so on are coming up with studies, many of which you will source back to the Catholic Church. One of those I was given was a thing called suicide contagion in Oregon. I was told about suicide contagion in Oregon, so I sat with Katrina Hedberg, who is the state epidemiologist at the Oregon department of health and is kind of a rain woman — she is Mrs Statistics. I said to her, 'What can you tell me about suicide contagion in Oregon?'. She said, 'It's true. Oregon does have a higher suicide rate than many states in America, but that has been the case for a long time, and we are not sure why'. Have those figures changed at all since these laws came in? No.

You will hear these arguments put, and doubtless have heard them put, that somehow or other magically our culture is going to change. I do not believe that is so; in fact I think the opposite is going to happen. I think a lot of what is hidden away in an unhealthy manner will come out into the open. For those who do not wish to

engage in the conversation — there are cultural and religious sensitivities — they do not need to. This is utterly voluntary.

Ms PATTEN — Thanks for all the work you have done for our committee. It has been great.

Mr DENTON — You have not got my bill yet.

Ms PATTEN — We could not actually afford to do what you are doing, so thanks very much.

Mr DENTON — Can I pick up on that point there and say that I really strongly hope there is funding for you to go overseas, because I think that is the no. 1 way to understand this.

Ms PATTEN — I will send you the health minister and the Premier's email addresses, if you like, to repeat that to them as well.

Mr DENTON — I am quite prepared to stalk them.

Ms PATTEN — It was very interesting you raising the suicide contagion, because we did have the Catholic archdiocese in this morning, and that is exactly what they raised.

Mr DENTON — My experience of the Catholic argument was summarised by a mighty speech made by Archbishop Fisher at the Sydney town hall. It is: these are people who claim the burden of proof is upon those who support these laws to show they are safe. I would like to see that question put back on them, because from my examination they do not really care much for the burden of proof. It is generalised, emotionalised, sensationalised statements: 'Put granny out of her misery', 'disposable groups in society' — meaning the disabled — 'suicide contagion', 'killing babies'. When you hold them up to the light — when you actually look at what happens — there are rational, compassionate, thoughtful, widely agreed, medical reasons for what has happened.

Ms PATTEN — That is right. I was just wondering if you had turned your mind to advance care directives. I appreciate the model that you have seen is the Oregon mixed with some of the definitions from Europe. With our advance care directives we can refuse treatment. We cannot ask for treatment. In your travels did you see any advance care directives that enabled a patient to say, 'When I get to this point, I don't only want you to stop giving me antibiotics, I want you to enable me to end my life.'?

Mr DENTON — That is a great question, and it speaks to the heart of probably the elephant in this room, which is dementia and Alzheimer's. This is, as you would expect, an ongoing but very advanced debate in other countries. In the Netherlands, where this is the longest running conversation — over 40 years now — even though their law states that it is possible for an advance directive to trigger euthanasia, they will not do it, even at the most advanced fringes, which is a thing called the Life-Ending Clinic that deals with complex cases, because the basis of these laws, the first foundation stone, is that you have to be a competent adult. The way the director of the Life-Ending Clinic put it to me was, 'You have to leave the ball at 5 minutes to midnight'. If you cannot say it — and not just once; it is not just an, 'Oh, yeah', it is rigorous — and if you cannot prove that your request is competent, persistent and clear, they will not do it. I think that has to be the foundation stone.

When I gave my speech at the Wheeler Centre some people, not surprisingly, wanted to argue with me about that. I have someone within my own family who is very heavily in the grip of Alzheimer's disease; I understand well the desire to help that person end their life. But you cannot have exceptions with a law like this. The law has to be clear, and more than that I think it is beyond reasonableness to expect any doctor to assume to know the mind of another and to act in that way.

I think advance directives are very important. I have been distressed to discover that many hospitals and doctors do not really know about them or pay much attention to them. It is certainly part of the conversation we have to have in this country, but in the end I think you must be able to speak for yourself and be competent and persistent.

Mr MELHEM — I have a follow-up on that. Let us say that a person is beyond that and is not able to make that choice. I can give you a case in point. My mother-in-law has for four years been confined to bed while dementia sets in. She does not remember anything and she cannot walk but she is comfortable. My wife has

power of attorney, both medical and financial. In that case, how can we stop, using this as an example, someone saying it is time for her to go — —

Mr DENTON — How can we stop — —

Mr MELHEM — How can we stop someone in that circumstance saying, ‘You’ve been here for too long. I don’t believe my mum wants to continue to live’. How do you then — —

Mr DENTON — Under the system I am proposing, which will be modelled on the system overseas, somebody could do that of course. They could do that now in fact, but they would end up going to jail —

Mr MELHEM — True.

Mr DENTON — because they have to put that case for review. They have to explain, they have to show — and remember there is a second doctor as well — how it was that the decision was made that that person was euthanased. They have to show that that person made the request. It would not take very long to discover from the medical records that that was not what happened. This is how our medical system works. We have a trust relationship with our doctors and with the regulatory framework that oversees it. This is no different but it is very, very particular.

Mr MELHEM — So you are saying to me that unofficially these sorts of things can happen now because there is no regulation. If you regulate the system, then you must follow certain criteria, which will probably give more protection than the current system. Is that — —

Mr DENTON — Absolutely, that is a very key point, Mr Melhem. When I was talking to the policy officer from the Royal Dutch Medical Society he was explaining all the safeguards and I said, ‘So really the system is impervious to abuse’. To my surprise he said, ‘No. There is no system that is impervious to abuse’. It was fairly early in my research and I thought, ‘That’s a red flag. You can’t say this’. Then I realised as he explained it further, he said, ‘No system is impervious to abuse, but we know what is happening in our system, who is doing it and where, and this system provides far greater safeguards than a country like yours where there is currently no system’.

Ms PATTEN — I have a quick question. The recent decision in the UK where we saw, surprisingly I think — —

Mr DENTON — A huge vote, yes.

Ms PATTEN — I was surprised by the vote there and the comments made by the MP who put that bill up. It was an Oregon kind of model, but it was the disability groups that were the most vocal in that. Have you got any thoughts about why that was voted down so overwhelmingly when we saw something quite different in Canada not that much before?

Mr DENTON — I am not really sure. My real focus has been on those three places so I have not studied England closely. I do understand that one of the determining factors was that the doctors were against, and one of the strong reasons they gave was that they felt this would affect doctor-patient relationships, which is particularly ironic because we know from overseas that it has affected doctor-patient relationships positively. I do not know exactly why it is. I suspect, and this is just a theory based on absolutely no research, that there is also something in that British stiff upper lip character, but that is just a guess.

The disability argument is one that I am really puzzled about. I met it right from the start. I did not see it in the research, and I have seen no credible evidence to support this idea that the disabled will be coerced. I have read a number of the websites — Not Dead Yet and things like this — which are febrile in their concerns. I know from speaking to people in the disability community, and I do not doubt for a second that their lived experience gives rise to genuine fear, but because their fears are real does not make them a reality, and I just see a disconnect there between what they fear is going to happen and what is actually happening.

One of the key pieces of my research was to move beyond the question of simply euthanasia and those who had skin in that game, and I went and spoke to representatives from key disability groups in Belgium, the Netherlands and Oregon, and I took to them all of the questions I had heard from the opponents about the disabled being coerced, being made to feel vulnerable, being devalued and being viewed as economic units that

were disposable. I put those questions to them not with any framing. I did not say, 'By the way, these are a bunch of questions which I am not sure about, but what do you think?'. I just put them to them one after the other. I particularly remember Pierre Gyselinck from the Belgian Disability Forum, who after about six of these questions got quite indignant and said, 'Why are you asking us this?'. I had to explain, 'I need to ask these questions in this way. I am asking them neutrally because I need to hear your honest answer'.

The long and short of this was that none of these organisations reported any abuse, and in fact they made the point that this empowered their members; it gave them choices. It is a very difficult conversation, because, as I said, I understand the disability community. Their fears are genuine, but as I listen to them I would urge two things of them. One is that they engage more closely with their fellows overseas and more honestly, and the second is bring those fears to the table. There are many within their community for whom these laws would apply who would welcome these laws.

Do not just turn the table over and say, 'Nobody can have anything if we can't have everything'. I think there is a radicalisation to their view of the world which is in excess of the facts of what is happening. We all know how sometimes our emotional view of the universe can get in the way of our ability to respond to what is actually happening. We are all capable of it; probably not me, but most likely all of you! I do believe that is what is happening here. I hesitate to say it because first of all I know this is a very vocal community and I know this engenders great anger in them. But it was interesting. I spoke to Bob Joondeph who is from the disability rights organisation in Oregon, whose job it is to represent the civil rights of the disability community, a man perfectly placed to know if there were issues. I said to him, 'Do you think it's a little bit patronising to suggest that somehow or other disabled people are more likely to be coerced than able-bodied people?', because the argument, as you would have heard, is, 'Our lived experience is that we are thought of as less, so therefore that translates to us thinking less of ourselves'. And he said, 'A little bit patronising? I think it's a lot patronising'.

There is an irony that these people within the disability community — who I do not believe represent the majority, I might add, but they are vocal — these people who represent the disability community who are so vocal about the coercion that they going to suffer seem to me to be the least likely people in the world ever to be coerced into anything.

The CHAIR — Mr Denton, we have not discussed Switzerland. Have you got any perspective — —

Mr DENTON — I have a very limited perspective on Switzerland. I really wanted to look at these three countries in depth. The only comment I have to make on Switzerland is that Switzerland is fascinating. It is rarely mentioned by opponents as an example of something that has gone wrong even though the Swiss laws you could write on the back of a beer coaster. They have almost done nothing. It is like an historical anomaly these laws exist, and it can be summarised as, 'As long as you're not doing it for personal profit, we are not going to prosecute you'. You would expect therefore, if logic followed, in a country with almost no safeguards, if logic followed from the opponents and this thing of the slippery slope, Switzerland should be a slippery crevasse. There should be tens of thousands of people falling down it, but there is not.

I cannot comment much more on Switzerland than that, other than it is a fascinating anomaly which seems to give a remarkable lie to this idea that somehow or other people en masse are going to rush to die. My favourite comment on this came from an Oregon doctor called Peter Regan, who when asked why such a tiny number of people were using their laws — in Oregon it is less than half of 1 per cent of all of the people who die — said, 'I don't understand why people expect there's going to be an avalanche anywhere. It turns out people just don't want to die'.

The CHAIR — Mr Denton, thank you very much.

Mr DENTON — Thank you for the opportunity. Again, if there is any way I can help persuade the political powers that be. I think going overseas is terribly important. The doctors I spoke to were not in lockstep. There were things within their own systems about which they went, 'I think this could be done better', but that was the example to me of a mature and thoughtful system. These were not zealots — these are people who have practised and worked within the system for many years, who know its intricacies and know its difficulties. I am sure none of us are under any illusions that this is a black-and-white and simple issue. Death is complicated, dealing with it is complicated, but what is missing in our national conversation right now is full understanding of what happens overseas and, in my view, genuine compassion towards people who are genuinely suffering. Thank you for the opportunity to appear. I really appreciate it.

The CHAIR — Thank you for appearing, and thank you for your submission.

Committee adjourned.