

JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

**INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA
TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS
REGARDING THEIR OWN END OF LIFE CHOICES**



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
FRIDAY, 13 APRIL 2018**

SESSION SIX

Members

**Ms A. Sanderson, MLA (Chair)
Hon Colin Holt, MLC (Deputy Chair)
Hon Robin Chapple, MLC
Hon Nick Goiran, MLC
Mr J.E. McGrath, MLA
Mr S.A. Millman, MLA
Hon Dr Sally Talbot, MLC
Mr R.R. Whitby, MLA**

Hearing commenced at 3.59 pm**Mr ANDREW DENTON****Founder/Director, Go Gentle Australia; Creator/Presenter, *Better Off Dead* podcast series, examined:**

The CHAIR: Thank you very much for speaking to us this afternoon, or this evening I think it is for you. On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson and I am the chair of the joint select committee. We have Hon Dr Sally Talbot; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; and Hon Robin Chapple here today. The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in Western Australia and to highlight any gaps that may exist. It is important you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege; however, this privilege does not apply to anything that you might say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. The audiovisual recording will be available on the committee's website following the hearing. Do you have any questions about your attendance here today?

Mr DENTON: No. That was a pretty clear explanation, thank you very much. And thank you very much for the opportunity to speak with you.

The CHAIR: It is a pleasure. Before we begin with our questions, did you want to make a brief opening statement for the committee?

Mr DENTON: Yes. I should explain how I come to be here. It came about by the very painful death of my father over 20 years ago, which led me to want to answer the question of why he had to die such a painful death and why we could not have laws such as those overseas to assist people to die. That has led, although I never intended this, to me spending the last three years full-time answering that question—travelling around the world to the Netherlands, Oregon and Belgium and around Australia many times, and speaking to people on all sides of this argument. I started my journey at an anti-euthanasia convention in Adelaide back in 2015. I have spent thousands of hours talking with doctors, palliative care experts, nurses, politicians from all sides of this debate on both sides of the aisle, ethicists, theologians, police officers, ambulance officers—you name it. Most particularly, I spent time with people who are dying and the families of those who have died and suffer terribly as they do so. That opportunity has been a great privilege.

I bring to this committee a great deal of experience in discussing the matters that you are now considering. As part of that experience, and appended to the Go Gentle submission, was this book *The Damage Done*, which is a collection of testimonies from around Australia from the families of those who have died and people who are dying, and from doctors and nurses, about what some would choose to minimise in this debate, or indeed make disappear, which is that there are people beyond the help of palliative care. Palliative Care's own words and statistics say this. There are people who die terribly in this country. There are people who take their own lives in appalling ways because they do not have the full range of compassionate choices at the end of life. A big part of what I have tried to do over the last three years, and what Go Gentle tries to do, is not just bear witness, but to keep in the eyes of those who are deciding on these laws the genuine truth about how some people die in Australia. I have watched, as I am sure you have, the royal commissions

unfold most recently into the banking industry and previous to that into sexual abuse in the church. As I watched those witnesses give their stories, I have noted not just my reaction but those of other Australians, as they begin to understand the actual human cost as opposed to arcane questions of legislation or high ethical debate, and they have begun to understand the human need for change. It is my firm belief that were a royal commission ever to be held into how people die in Australia and the reasons for that, laws about assisted dying would be written within a year.

While I understand that there are serious medical, ethical and legal questions around how to frame such laws, from my research and my direct knowledge, I believe there are undeniable reasons why these laws should exist. More importantly and more relevantly, it is very important to understand that in Australia already we do have laws which allow people to hasten their own death, but they are in fact cruel laws. We legally allow people who are dying to suicide. We wish it did not happen, but they do. As your own coroner has told you, as the Victorian coroner told the Victorian inquiry, and as the South Australian coroner, Mark Johns, told me, they are doing it on a regular basis in terrible ways. We do legally allow people who are dying, and Palliative Care accepts this, to refuse all treatment and to allow starvation and dehydration, in combination with their disease, to end their life. We have not given doctors the power to do this, but largely without scrutiny or the need to report, we give doctors the ability to terminally sedate a patient; in essence, the foreseen outcome of that is that the patient will die—that is, to end their suffering. What that means is that that patient does not get a chance to say goodbye. Their family have to stand around the bedside waiting for them to die.

We are not starting from a blank page here when we talk about assisted dying. We have already accepted the principle. But what we are saying to Australians is that if you are dying and beyond medical help, yes, you can choose to hasten your death but you must do so slowly and painfully, not just for you but for your family. You cannot do so quickly and mercifully with the clear help of the medical profession. I am very much looking forward to the opportunity to discuss the many different pathways that this question takes us down.

The CHAIR: Thank you for that. You have obviously watched closely the processes more recently, probably in Victoria and New South Wales, around legislating for broader choices at the end of life. Why, in your opinion, did the Victorian bill succeed where the New South Wales bill failed?

Mr DENTON: It is complex. I think one of the undeniable things that is happening allegedly in Australia is that there are strong religious forces in different Parliaments in different measures. In New South Wales, there is the Catholic right in the Labor Party and the rise, I guess you would say, of the Christian evangelical force within the Liberal Party. I make no comment on that—that is what democracy is—other than to state that if you are coming from a religious viewpoint, no matter your politics, then the idea of assisted dying is just not to be considered; it must be and will be opposed, regardless of the evidence. So I think that is in play in New South Wales. But I think a far more important thing informed what happened in Victoria. I watched that process very closely from the initial report of the committee right through to the passing of the law at the end of last year. It was threefold. One was that they set in train a proper, long and strong consultative and deliberative process. The original committee was multiparty. It was chaired by a Liberal MLC. It had a full range of views on that committee. At the start, there were two very strongly in support of the law, two very strongly against—none of whom moved their positions—and four in the middle, including the chair, who remained to be persuaded. I think a very, very crucial thing that they did was not only did they receive an enormous amount of information from within their own state—they spent 10 months and a number of public inquiries going around Victoria and speaking to all parties—but they went overseas to see for themselves how these laws work. I know for a fact that for those members of the committee who moved from unsure to yes, it was that trip and understanding, from speaking

to a broad range of people overseas, including opponents of these laws, that in fact the laws do work safely and as designed.

Secondly, the Victorian government decided upon legislation. I think absolutely key was that it was the government that put forward legislation. I do not mean that in a political sense in terms of party politics; I mean that the machinery of government was able to swing into place. That meant that the Department of Health and Human Services and all that bureaucracy was able to do what then became another broad consultative process, which was the advisory panel set up under Professor Brian Owler, the former head of the AMA. They then spent a further nine months consulting around the state again with all bodies that were involved in this, including some strongly opposed, such as Palliative Care Victoria. They spoke to nurses, they spoke to individual practitioners, they spoke to hospitals of all stripes, and they were able to inform the legislature. The bill was then thoroughly debated, as you will probably know, for 100 hours in the Victorian Parliament. The reason I hold out it being a government bill as being the crucial difference between this and every other attempt in the last 20 years to pass this legislation is that all those other attempts have been, in one measure or another, private members' bills. They might be groups of politicians from different parties putting forward the bill, but, whichever side of the debate you are on, this is an enormous piece of legislation to debate, to understand and to frame. Nobody wants to get this wrong. Everybody has the same intention here, which is to help people better at the end of life. It requires that level of capacity and commitment and widespread consultation for the right legislation to be framed. I cannot emphasise enough how that is my absolute belief.

[4.10 pm]

I also spent a lot of time in South Australia, where you may recall the legislation was defeated by one vote, where that was a private member's bill. I have seen both up close. It is my absolute belief that for this legislation to pass, and not just to pass, but to pass properly framed and considered, it has to be a government bill, supported by the machinery and bureaucracy of government.

The CHAIR: From the point of view of an advocate for voluntary assisted dying, which was the better bill?

Mr DENTON: Between South Australia and Victoria?

The CHAIR: Between New South Wales and Victoria

Mr DENTON: I believe the Victorian one. I think the process was really impeccable. It is interesting to me, having looked at New South Wales and South Australia quite closely and Victoria. I do not know what it is historically that has not made Victoria—the way they went about creating that legislation was deeply considered and far in advance of what I have seen in the other states.

Hon NICK GOIRAN: Mr Denton, it is interesting that you say that the Victorian legislation or bill was better than the New South Wales one in your view. We heard earlier today in a public hearing from a gentleman, Marshall Perron. Do you know Mr Perron?

Mr DENTON: Yes, I do.

Hon NICK GOIRAN: His view was that the New South Wales legislation was superior in part because the Victorian legislation was too restrictive.

Mr DENTON: Yes. Did Mr Perron elaborate on that?

Hon NICK GOIRAN: I would have to go back to the *Hansard*.

The CHAIR: It is a long day.

Mr DENTON: Yes.

Hon NICK GOIRAN: It is interesting that he and others have suggested that Victoria is too narrow and New South Wales was superior.

Hon Dr SALLY TALBOT: He was essentially talking about the time periods.

Hon NICK GOIRAN: This could possibly be the first time I have heard someone say that the Victorian one is superior to the New South Wales legislation.

Mr DENTON: Part of the reason I think it is superior is that it has become a law. I think part of the issue and problem with this debate over 20 years is that there have been attempts to pass a very wide piece of legislation through a very narrow political reality.

Hon Dr SALLY TALBOT: Mr Denton, first of all, thank you for the book, *The Damage Done*. By bringing those stories together, I think you have played a very important part in helping move the debate along. Any of us who have been involved with somebody who has died under those circumstances saw our own stories written there. I think it is very powerful, so thank you for that.

I wanted to ask you about a couple of elements of the debate, recognising your experience and the number of people you have talked to. I wanted to come, first of all, to that argument that says that we ought to be doing more for palliative care—that it is an either/or situation; that if you endorse voluntary assisted dying, somehow you are taking resources away from palliative care, which of course was the argument put by Professor David Kissane in Victoria. We had a witness a couple of months ago who was quite rude about your rudeness about Professor Kissane, and took great exception to that. Can you talk a bit about that argument and how it is presented?

Mr DENTON: I am not sure what rudeness they are referring to. I did point out that Professor Kissane is a member of the Order of the Knights of Malta —

Hon Dr SALLY TALBOT: I think he mentioned that, yes.

Mr DENTON: — which is a very high order within the Catholic Church who are sworn to defend their religion. I point that out because if you are sworn to defend the Catholic Church, then you do not have anything approaching an impartial view of voluntary assisted dying. In fact, you are sworn to oppose it at all costs. I do not believe that is rudeness; I think that is clarification. I am really glad you raised the question of palliative care versus assisted dying. Speaking for myself and every other advocate that I know for voluntary assisted dying, we are the deepest supporters of palliative care that you will find, because palliative care and voluntary assisted dying are the same thing. What is palliative care? What is palliation about? It is not just about assisting people to die; it is about assisting people to live as well as they can as they die. I think before the Victorian law was passed, only once has this question of assisting someone to die been tested in any formal tribunal in Australia. That was the Medical Board of Australia versus Dr Rodney Syme. Dr Rodney Syme had offered to supply life-ending medication to a patient called Bernard Erica, who had cancer of the throat and tongue. Through a long set of circumstances, Bernard Erica's GP found this out and reported Dr Syme to the Medical Board of Australia, which then took action in the Victorian Civil and Administrative Tribunal, alleging that Dr Syme was a danger to his patients and should be made to stop. Dr Syme put forward as his argument that he was not offering medication to help Bernard Erica to die; in fact, it was not for him to know whether or not Bernard Erica would use that medication. As we know from overseas—Oregon being the outstanding example—more than 30 per cent of patients who get life-ending medication choose not to take it. He was offering Bernard Erica this medication as a means of control. What you will often hear in this debate, as people try to explain why we should not have these laws, is that dying is not just about pain; dying is about suffering, of which pain can be a significant part, but suffering is manifold, and part of that suffering, as you are dying of a disease, which only has one trajectory—it is only going to get worse—is the

loss of control, the loss dignity, the great fear that comes with it and the knowledge that no matter what medical science does as you are sucking on those endo lollies and as you are doing the best you can to deal with the degradation of your life and your body, you know it is just going to be terrible. I met Bernard Erica. Under the laws as they existed then, there are only those choices I mentioned before: take your own life; refuse all treatment, which is a horrible, slow way to go; or get them to put you into a coma, after you have been suffering for however long. Bernard Erica in his submission to the inquiry said, “None of the doctors who have been treating me, however good their care has been, has offered me the relief from what is existential distress.” That is not a philosophical, Jean-Paul Sartre reference. Existential means your existence—the distress of your existence. No-one was able to offer him that level of understanding that, should this get beyond a point where it was worth him living, he would have any control over the situation, other than Dr Rodney Syme. What he said was, “What Dr Rodney Syme offered me was clear palliation.” The tribunal found unanimously in Dr Syme’s favour—that what he was doing was absolutely consistent with the aims of good palliative care, which is to assist someone to live as well as they can while they die. They furthermore said that the Medical Board of Australia, in denying these rights, was being unreasonable to patients in that situation. There are many people within palliative care, including, most significantly, the most senior palliative care physician in Australia, Dr Ian Maddocks, who have stepped forward over recent years to say exactly this—that voluntary assisted dying and palliative care are the same thing, as they do overseas. In Oregon, 90 per cent of the people who use this law are also in palliative care. In Belgium, their laws came from within palliative care; it sits within their palliative care system. In the Netherlands, it is recognised absolutely within the palliative care system. This is not a binary argument; it never should be about voluntary assisted dying versus palliative care. Regardless of where this debate goes in your state, as I have seen happen in Victoria, South Australia and New South Wales, the simple fact of having this debate does a very important thing—it raises the understanding of palliative care, and it raises the realisation that this is an important service and it needs to be understood and well-resourced and well-funded. But, within that, sits the absolutely documented reality from within palliative care itself—that no matter how many resources you throw at it, there are people they cannot help, and that is who this law is for.

[4.20 pm]

Hon Dr SALLY TALBOT: Can I ask you also about the attitude of doctors to voluntary assisted dying laws? I ask you for two reasons, one is that we had submissions and hearings from and by the AMA. The AMA in Western Australia are not in favour of voluntary assisted dying laws. We have also heard from a general practitioner who was opposed to any change to the law, telling us that in Canada, for example, no doctors will make themselves available to administer the provisions under the law. What is your view about the bind in the medical profession in Australia?

Mr DENTON: First of all, I would question that idea that no doctors have made themselves available in Canada, because some hundreds of people have already availed themselves of that law and I am sure they did not do it on their own, so that just seems to be wildly inaccurate. It is no surprise that there are doctors—and we see this overseas, that it is pretty much split down the middle for whom the Hippocratic oath, “do not harm”, they interpret that is, “We mustn’t ever do anything that is going to assist a patient to die.” That reflects in many ways a division within society, although our society shows that more than 70 per cent of people consistently do support the idea of assisting a dying person to die. We are seeing this change within the medical profession. I think it is very interesting that the Australian Medical Students’ Association last year, along with the Royal Australian College of General Practitioners, both moved their position to one in support of these laws. But let me address the AMA specifically. The AMA represents about 30 per cent of our doctors,

slightly less than a third, and even within their own ranks the split is about 45 per cent for, and 55 per cent against. All this tells you is that different human beings have different morals and ethics, and there is nothing wrong with that. The very core of any voluntary assisted dying law is the word “voluntary” and it respects and protects, as it should, any doctor’s right to not participate in this. However, for those doctors who believe “do not harm” means, “we could never assist a patient to die”, there are equally doctors—some of those testimonies are in *The Damage Done*—who believe that to leave a dying patient to suffer needlessly is to do great harm. And regardless of what doctors may think—only a small percentage of us are doctors, but all of us are human beings who are going to die—this is not a law for doctors, even though, importantly, a law like this will protect doctors in a way they are currently not protected, should they assist a patient to die. This is a law for patients and I think in this conversation, the patient’s voice, the patient’s right to have a choice, the patient’s right to determine that inevitable and most crucial thing in life, which is how we die, is overlooked and too often we look at this with the framework of: how do doctors feel about it? And part of what I have been trying to do over the last three years is tip the balance back to, “Wait a minute, this is actually about how we die, not about how doctors feel about how we die.” Any such law will exempt any doctor who does not wish to participate from participating. And I think that should never be lost either.

Hon Dr SALLY TALBOT: My last question is in two parts, Mr Denton. It is about the assessment of capacity. I wonder if you have a view about who should be doing the capacity assessment. The psychiatrists say that it should be them or some other specialist, a gerontologist or a palliative care specialist. What is your view about general practitioners? My second question, which leads on from that, is: can you envisage any kind of provision in a VAD law that allowed people with dementia to access the provisions?

Mr DENTON: Really good questions, thank you. This was debated extensively in Victoria and also in South Australia. I think where the Victorian law landed was very wise. Let me start by saying that in Victoria the peak psychiatry body did not want to be the gatekeepers. They made it very clear that they did not want mandatory assessment and senior psychiatrists there, Dr David Copolov and Dr Steve Ellen in their submissions to the inquiry spoke about the capacity of medical practitioners to assess capacity in patients. The starting point with medical treatment around Australia is that it is assumed a patient has capacity to make decisions, so we already ask GPs to make an assessment if they think that patient does not. Obviously, with a law like this, where it becomes a more critical question, what you are looking for is to make sure that GPs do have a focus on capacity. Where the Victorian law landed was first of all, any doctors that were going to participate in this law had to have specific training focusing on assessment of capacity. But more than that, and this is where the Victorian law is very skilfully framed, as you said before, it did not necessarily have to be just that GP. If, for instance, it was somebody who is very elderly, then you could, as you would in any other kind of medical practice, refer to a gerontologist, you can refer to a specialist who may have more expertise in that level of capacity. I believe that the Victorian debate on capacity showed that not only is there already an accepted standard under which the medical profession operates, which we have been very happy to accept in terms of assessing capacity, but you can improve on that if you so desire, for a VAD law.

The question of dementia is actually the hardest one in this. In the Netherlands I spent time with a family whose mother had not only been diagnosed with dementia but, under their euthanasia laws, had been euthanased. And not just the family, but what is called the life ending clinic, the specialist clinic that deals with these very difficult cases, what I came to understand was that the hoops she had to go through to prove her understanding of her request, were many and significant. However, that being said, in Belgium and the Netherlands—the two places where people with dementia can

legally be assisted to die; Canada is leaving its options open on it—there is division between doctors about whether or not this is something doctors should be doing. I strongly understand why they feel that way. I think it is a very, very difficult question. I do not think any doctor should be put in the position of assisting someone to die if they are not sure that that person is capable of making that request. Having said that, as I have gone around Australia speaking about this over the last three years, it is the number one question I am asked, and without fail it is the number one example I am given. We know that one in four Australians over the age of 80 suffer from dementia or some form of dementia or Alzheimer's. Even though I have seen the Netherlands model and I have admiration for it, I personally am not sure how it would be framed to help people with dementia in a way that does not put doctors in a very, very difficult situation. That being said, I do not think this is a question that is going to go away and whether it is addressed now, or in 20 years' time or 40 years' time, I think at some point, if this level of degenerative dementia in our society continues and possibly increases, then as a society we are going to want to work out how we deal with it. Personally, the laws proposed in Victoria, New South Wales and South Australia, none of them included dementia and I think that is right; the basis of the law is, you have to have capacity.

[4.30 pm]

Hon COLIN HOLT: Just on a follow-up to Dr Talbot's questions around capacity, what about the interaction with enduring powers of guardianship and advance healthcare directives. Obviously, voluntary assisted dying requires a voluntary agreement with capacity. Do you have any comments around the interaction with those instruments?

Mr DENTON: I think they are very important instruments, and, again, one of the things I strongly admire about the Victorian committee of inquiry is that voluntary assisted dying was only a small part of their report; most of it was on palliative care and advance care directives. I think they are very important things, but, again, I think for voluntary assisted dying, the patient has to be able to competently, clearly and through a series of steps request that process, and also, because it is voluntary, except in very specific cases where they cannot swallow, I think they take the medication. So I do not think it is a case of an advance care directive that anybody else can action this law. It is worth noting that in Victoria under their Medical Treatment Act, families of patients, for instance, can request that they be taken off life support, and that has been since 1988. You will hear, and doubtless have heard, arguments that people can be coerced into dying under these laws. It is interesting that in Victoria in the 30 years that the Medical Treatment Act has allowed this, there have been no instances documented of a family acting in such a way as to get monetary or other gain from having used the Medical Treatment Act to end the life of a loved one. I mention that because it is worth keeping that framework in mind when we talk about how things operate in real life.

Hon NICK GOIRAN: Mr Denton, I just want to talk about doctors and their role in the safeguarding process. At page 41 of your submission, you deal with this issue and you say that with regard to safeguarding against coercion and elder abuse—I should just declare that at this point in time I am chairing a committee of the Western Australian Parliament that is looking into the issue of elder abuse—in Victoria the application process itself safeguards against coercion. I will leave that to one side for a moment. Then you go on to state —

The second major safeguard is the conservatism of the medical profession—the professions' ethic to help their patients to go as far with their lives as possible while respecting their autonomy, and their concern to protect the vulnerable, which includes suffering, dying people. This conservatism should not be under-estimated.

How do we protect the patient if the doctor is not conservative?

Mr DENTON: That is a very good question, because I think it brings into light the entire process of how this works—I am now talking about the Victorian model, but it is very similar to those proposed in other states—which is that the only way you can access this law in the first place is you have to be clearly dying. That does not come out of the blue. You do not walk into a doctor's surgery and get a stamp saying, "Yes, you're clearly dying and I'm going to sign off on the prospect of you being given a lethal medication." If, for example, you have a degenerative disease such as motor neurone disease or multiple sclerosis, if you have advanced cancer, you have a long medical history, and it is not just your doctor, but it is a whole number of medical institutions that have that history. The way the law is framed, as it was in Victoria, is that there is not just one doctor, but there are two, so one doctor's work is measured against another. Unlike all other end-of-life decision-making that we currently do, where there is zero review, oversight or scrutiny of end-of-life decision-making, this law requires that doctors' actions are very, very closely examined. They are accountable for what they do. It is not just the doctors; there is the Department of Health and Human Services, there is the Voluntary Assisted Dying Review Board, there are pharmacists, there are witnesses, and there are signed witnesses. So, unlike now, where we know from evidence—not as much evidence as I would like, but we know for a fact—that doctors do illegally assist people to die in Australia, faced with patients with horrendous suffering, unlike now when there is absolutely no knowledge about whether or not they might be coercing those patients, and unlike now with terminal sedation where there is no oversight and no review and where it is just down to the doctor's intentions, we are very happy to accept that all those doctors acted with the best possible intention. We do not question even for a second whether coercion may have been involved; we do not question for a second whether there might have been some conspiracy with the family. We just go, "That is fine; we trust doctors." But the argument made against a voluntary assisted dying order, that somehow that system, where there is no oversight, no review, no scrutiny, no guidelines and no accountability, is a safer system than a voluntary assisted dying law which has all those things.

I accept that the question of elder abuse is a very real question, and it is absolutely appropriate that it be discussed and examined closely in this debate. I would make the point that it is also coercion to force an elderly dying person to suffer horribly for days, weeks or months as they die. But putting that to one side, the reality is, and I am sure you know this, Sir, is that a lot of elder abuse happens because it happens out of sight. That is why it happens—because people cannot see it. That is why people think they can get away with it. Remember, again, under the Victorian model that those doctors who wish to participate were trained specifically to question and identify elder abuse, something which currently does not happen. Under this law, it virtually mandates that a light is shone on this area. I think as a general principle that is a healthy thing. I have some sense that you would know a great deal more than me of the darkness that lies around elder abuse, and this law casts light on that darkness.

Hon NICK GOIRAN: In your investigation, did you get a chance to review the Northern Territory cases?

Mr DENTON: The four cases or, as Dr Kissane would suggest, the seven cases?

Hon NICK GOIRAN: Either/or.

Mr DENTON: Well, it was four. I have not reviewed them closely, personally, one by one, no. The Northern Territory cases took place, you may recall, in an extraordinarily heated atmosphere. It is very different from where we are now. Just to give you a sense, that was 1997. That was the first law written in the world. Four people died then under that law before it was repealed. These same kinds of laws are now available to over 100 million people around the world, so the whole thing has moved on a lot further since then. They happened in an atmosphere of extreme heat, where the

AMA in the Northern Territory was warning doctors off against helping anybody because they would be liable for legal action. What happened under that law—and you will recall that federal politics came it into very quickly; there was enormous media attention—I think was deeply distorted. I do not think doctors acted as they would now and I do not think patients were given the help that they would get now.

Hon NICK GOIRAN: So was the conservative culture of the medical profession that you referred to more conservative then in 1996 or is it more conservative now?

Mr DENTON: I cannot give a definitive answer to that, except to say that I think it is less conservative now, and I do not even say this critically. I think it is a very interesting conversation within the medical profession. Look, I have a great deal of empathy for doctors. One of the things that surprised me most in the last three years which I had not understood was I just assumed that doctors were comfortable with end of life—you know, that is part of their gig. But, in fact, I have discovered that many doctors are deeply uncomfortable with the question, struggle with it, struggle with talking to their patients about it. There was a survey done of, I think, oncologists in Brisbane that showed that something like 80 per cent of them gave what they would refer to as futile treatment rather than have the conversation with their patients. But I think what has happened is that the mantra within the medical profession is about patient-centred care, so I think that in many ways expresses the evolution of medicine in Australia. You know, when I was a kid—I am probably looking at you, older than most of you, and Mr Chapple may be the exception; it is the beard, I am sorry —

Hon ROBIN CHAPPLE: That is all right, son!

Mr DENTON: The doctor was god; what doctors said went—that was it. But now, not only from a patient's point of view, from the doctor's point of view, the idea is that you consult. In fact, you consult on all areas of medicine, including how much chemotherapy you are going to have, other than, ironically, on how you are going to die. I think that where medicine needs to get to is another word, which is patient-directed care. It is not just about consultation; it is about: "What do I actually want here?" We accept that a patient who has cancer and might have had 10 lines of chemotherapy does not want the eleventh. We accept their right to do that. We should be accepting their right to direct their care at the end of life.

[4.40 pm]

Hon NICK GOIRAN: I am a little troubled that you say to the committee that the doctors are less conservative now than what they were 20 years ago if the conservative culture is to be the main safeguard.

Mr DENTON: No, you misunderstand me. You are taking the words "not conservative" as meaning reckless. Consultation with a patient, which is what I am advocating, is not being reckless. Consultation with a patient is being a good doctor.

Hon NICK GOIRAN: Could a good doctor make a mistake?

Mr DENTON: Any doctor can make a mistake. They can make a mistake now. They can make a mistake now withdrawing treatment. They can make a mistake now giving treatment. We know that. If what you are arguing for is a perfect system, then I suggest you pack up your inquiry now. If your Parliament has ever passed a perfect law, I would like to hear about it. What we are looking to do is create a law which mitigates harm in the community. There is clear harm happening in the community and if the argument is that a system where this happens in the dark with no regulation, rules or accountability, is better for patients and society than a law which supplies those things, then I think it is a poor argument.

Hon NICK GOIRAN: Do you think there is a difference when a Parliament makes a law, perfect or otherwise, when the end outcome is the guaranteed death of the citizen?

Mr DENTON: That is not the outcome, first and foremost. Let us be very clear. I will go back to Oregon and go back to that Victorian Civil and Administrative Tribunal finding; that patient is going to die. They are dying, that is why they have accessed the law, so we know that is going to happen. Whether or not they use that medication is an unknown. Currently in Australia, there are decisions made every day where we know the outcome is death. Doctors make those decisions, legally supported by the laws of the land passed by Parliaments. Withdrawal of life support, withdrawal of medical treatment—we know that those decisions are going to lead to a patient's death. That principle is already accepted. This sounds too aggressive, but I think it is a debating point to say, "Yes, but what if this will lead to the death of a patient?" Death happens to all of us. The question is how we get there. How do we live as well as possible until our death? That is the business of Parliament.

Hon ROBIN CHAPPLE: Mr Denton, it is the young Mr Chapple here. In relation to motor neurone disease, it is obviously one that is presented to us as a significant problem. We talk about capacity, but obviously at various stages, it is difficult to discern, with motor neurone disease, depending on the length of it, whether you have capacity or not. We have talked about the Victorian model, which looks at that six-month period. There is an extension to 12 months for people who are suffering in other ways. We quite obviously have had evidence here that you can get people who are going to be in almost a vegetative state for much longer than that period and well beyond capacity. How do we deal with people in that situation who are obviously in intolerable suffering?

Mr DENTON: That is why, in the end, where the Victorian law ended was with six months or less to live, but with exemptions for neurological diseases such as motor neurone disease. That was an understanding of the reality that you have just described. Motor neurone disease, colloquially known as the bastard, basically strips your life from your bones as you live. The trajectory to death is clear, but the timing is not. You can actually lose, not your mental capacity, tragically, but you can lose all your physical capacity to do anything, including swallow, over a period many months out from when you might actually die. That is why I think it was a humane and necessarily humane thing to extend that law to 12 months for those cases. I do not know if that answers your question.

Hon ROBIN CHAPPLE: Two things arise from that, Mr Denton. Is 12 months long enough in the case of motor neurone disease; and secondly, arising from that, we come to the issue of patient self-administration or medical doctors' administration. It is all tied up in that whole thing. Do you think we need more than 12 months and when it gets to the point where an individual with motor neurone disease or whatever might have given an advance health care directive and is going to die, but does not have the physical capacity to self-administer, what happens there? I obviously know that you do not know, but I am looking to you for advice.

Mr DENTON: On the question of 12 months, all the advice I have had from senior medical people, including Professor Maddox, Dr Roger Hunt and Dr Brian Owler, is that 12 months would encompass the vast majority of people with those diseases. To the question of self-administration versus doctor-administration, this is something that I feel very strongly about. One of the things I appended to our submission were links to the podcast series I made called, *Better Off Dead*. In one of those, I think it is episode 15, there is a story of a palliative care nurse called Ray Godbold who was dying of advanced oesophageal cancer. The reason these fall into the same category is that what it meant was that he was going to reach a point where he could not swallow and he was faced with this terrible arithmetic. He did not legally have nembutal, but this terrible arithmetic of: "Do I end my life earlier than I wish to before I can no longer swallow, or do I take my chances?" and he got it

wrong. Everything that he feared would happen to him and his family, happened. His death was horrendous. It deeply traumatised his family, and yet had a law existed where, in those clear cases, for example, imagine someone with quadriplegia had advanced cancer or motor neurone disease; is it really fair—I would argue it was cruel in the extreme—to say to them, “No; you cannot have access to this medication, but anyone who swallows can.” Interestingly, when I went to Oregon, I made a particular point in Oregon and also in the Netherlands, of speaking to disability rights groups to see whether the alleged abuses of those groups had happened. The director of Disability Rights Oregon—a man called Bob Joondeph—said in the 17 years that their law had run, they had only ever had one complaint within their community, which was from a man with quadriplegia who felt their law discriminated against him because it requires you to drink the drink. So I think it is not only essential but, as I said, it would be cruel in the extreme not to allow doctor-administered medication in those very particular and very clearly identifiable circumstances where a patient cannot swallow or ingest medication.

The CHAIR: Around the issue of eligibility, we have heard a lot of evidence around chronic illness and terminal illness. We have also had evidence from older people in our community who want the ability to end their lives when they choose, whether or not they have chronic or terminal illness, but when they get to a point in their lives when they do not feel it is worth continuing anymore. What is your view on that?

Mr DENTON: I deeply understand this. I think there are many older people who do not have what we call a terminal disease who have so many different illnesses and ailments that their life is absolutely miserable. Their life is full of suffering. I deeply understand that. I know in the Netherlands and Belgium that under their law, which is very differently framed to other places, which refers to unbearable or unendurable suffering, that they do allow cases of people with multiple ailments but not necessarily a terminal disease. Personally, I think that is a humane thing to do but I think politically in Australia, it is probably not an acceptable thing to do. I think regardless of what law you write—this exists even in the Netherlands, which has had the longest and deepest conversation about this of any society on earth—their remains societies, like Dr Nitschke’s Exit in Australia, an organisation about which I have mixed feelings, that supply the means to people, or supply the advice to people to get the means, for people such as you have described, to end their life as they choose on their own terms. I am aware—I have interviewed Dr Nitschke—that I am to him as those who oppose these laws are to me; he would argue that, “But you are just actually not sectioning off a particular group of the community.” In some ways, that is true, but that is because I believe, as I said before, that there is a political reality in this country. We have to write laws that suit our society and that suit our medical profession. So I understand where that desire comes from but it is my belief that it is not a political reality in this country at this time.

[4.50 pm]

Hon NICK GOIRAN: It is not every day we have Mr Denton appear before us, so we must make the most of the opportunity. You have spoken to a lot of individuals in organisations, no doubt not just in Australia, but internationally. Have you had much to do with the Royal Australian and New Zealand College of Psychiatrists?

Mr DENTON: Not personally, no, but I have certainly read material from them.

Hon NICK GOIRAN: Have you had an opportunity to consider one of their concerns, which is with regard to the work of consultation-liaison psychiatry and the risk that where a patient has a terminal condition causing suffering, symptoms of mental ill health may be mistaken by a doctor not trained in psychiatry for an understandable reaction to their condition?

Mr DENTON: Again, this was debated more clearly in Victoria and I repeat that the peak psychiatric body there did not feel that psychiatric consultation is mandatory, but what the law allows—is if the doctor has any doubts about capacity or any other thing in a patient's request, they can refer them for psychiatric examination. I think this gets back to we trust our medical profession, interestingly not as highly as Belgium and the Netherlands and Switzerland do. They have some of the highest trust in their medical profession of all the countries in the world. We trust our medical profession and we trust them to make complicated judgements every day in our hospital system and in their offices. Part of that is we trust them to be assessing capacity, including, right now, patients who have advanced cancer, who are making decisions about, for example, chemotherapy, or patients with degenerative diseases who are making decisions about their treatment options. I do not suggest that this is uncomplicated, but it is not uncomplicated in any area of medicine. I think that that understood principle as mandated by the law of Victoria that doctors can and, indeed, should refer if they have any doubts answers that question.

Hon NICK GOIRAN: Yes. You have said a few times this afternoon or this evening for you that—you use the word “we”—we trust our doctors. I should perhaps disclose to you that before entering Parliament, I was a barrister and solicitor in Western Australia and part of my practice was medical negligence law, so I guess perhaps when you say “we”, as a society there are degrees of trust. Some of us are, perhaps through painful lived experience of our clients, a little less trusting than others. Be that as it may, I am interested in your comment there that the peak body in Victoria did not think mandatory psychiatric assessment was necessary or appropriate or desirable. Was that peak body the Chief Psychiatrist in Victoria?

Mr DENTON: No. I am sorry; I actually forget the name of the peak body, but I can certainly come back to you on that. I will take that on notice. I have just been told that I can take it on notice, so I have, or you can take it on notice. I will come back to you with that. They made it very, very clear they did not wish to be the gatekeepers, that they did not feel it was their role to be the gatekeepers in this form.

Hon NICK GOIRAN: If you could take that on notice, that would be wonderful, because our Chief Psychiatrist in Western Australia has given some different evidence. Given that he is the Chief Psychiatrist in Western Australia, you will understand that we might want to give some weight to his views. But another eminent doctor here in Western Australia, Dr Lisa Miller, is an interesting doctor because she is the only one in Western Australia who is co-trained in psychiatry and palliative care. She has given evidence to the committee about this concept of demoralisation. In your investigations has that come up at all?

Mr DENTON: Yes. Dr Kissane has talked a lot about demoralisation as well. It appears to me that if you have a terminal diagnosis or a severe degenerative disease, it would be an almost unnatural reaction not to react to that in a way that is demoralising, but I think it is very easy, and I have seen this come many times, to overemphasise that. The reason people choose to access these laws is not because they are demoralised, not because they are a burden, not because of loss of autonomy, not because of pain, not because of loss of dignity. All those things are part of it, but the overarching reason and the only reason these people can access these laws is they are dying. They are dying. They are clearly dying and they are seeking help as they die.

Hon NICK GOIRAN: You did say that earlier and I have made a note of that. You need to be clearly dying, I have a note you said earlier, in order to be able to access this. But you conceded earlier that doctors make mistakes and one of the interesting things out of the Northern Territory cases—I respect the fact you indicated that you have not had the opportunity to review those cases—was

one of them involved a patient for whom one oncologist gave the patient's diagnosis as nine months, yet a dermatologist and a local oncologist judged the same patient to be not terminally ill. So it strikes me as a classic case where you have two experts, and one says, "Sorry, you have obviously got a terminal illness and your diagnosis is nine months", and the other person says, "Well, you are not terminally ill." That person would be in a spot of bother if the criterion is you need to be clearly dying.

Mr DENTON: I guess there is two things to say there. The first is to say that the deepest human urge is to live. So, the example you are giving is the assumption that somebody wants to die. You do not take this medication because you want to die; you take it because you are dying. I guess the other interesting thing to say is that research shows that there is no perfect science to diagnosis and doctors, by some considerable margin, are over-optimistic in their diagnosis of terminal patients. They give them longer to live than they actually turn out to live. There is a great deal of evidence to support that. If you are talking about doctors making errors in an imperfect science, then, unfortunately, they err on the side that is not most useful to the patient. This gets back to the question of allowing the patient to make a decision in the face of a terminal diagnosis. This is why sometimes cases are raised. In Oregon somebody lived two years beyond diagnosis; something must be wrong with the law. What that tells you is the law works as it should. If the law was not working, that person would have ended their life, but in fact they stayed alive for another two years. They stayed alive for as long as they possibly could before their disease got the better of them.

Hon NICK GOIRAN: I think you just said the deepest human desire is to live.

Mr DENTON: Yes.

Hon NICK GOIRAN: Sadly, in Western Australia on average, we have one Western Australian per day who obviously holds a different view.

Mr DENTON: That is right. As your coroner pointed out, a number of those suicides are to do with people with terminal and debilitating diseases, and as we saw in Victoria and as corroborated in South Australia. I mentioned before if there was a royal commission, I believe this is at the heart of this question. The arguments against these laws is almost that they do harm, yet how can we turn away from the clear and actual harm being done by the fact that there are people beyond the help of medical science who are taking their lives in these ways. I think it is a good point you raise and a serious point and very much at the heart of what I hope your committee is considering.

Hon NICK GOIRAN: Mr Denton, I am getting some strong vibes from the chairman that I need to wrap up because we have extended our time. Can I just say this: first of all, thank you for the generosity of your time today and the frankness of your evidence. Secondly, this is a request and obviously you are under no obligation to do this, but I just encourage you, if you get the opportunity—you may or not wish to take this on notice—to have a look at submission 391 that has been provided to the committee. That is by that group that I referred to earlier, the Royal Australian and New Zealand College of Psychiatrists, and what I describe as their interesting remarks on this issue of the suicide of the elderly. By all means, if you would like to provide some kind of response given that we have run out of time, I would welcome the opportunity to read it.

[5.00 pm]

Mr DENTON: I will be sure to read it and sure to give you a response. I think that suicide of the elderly is very much at the heart of this issue. That is why I so strongly believe that this law needs to be written. I think it is a very dark thing in Australia and there are many reasons but, clearly, one of the primary reasons is the lack of end-of-life choices.

Hon NICK GOIRAN: Thank you.

Hon COLIN HOLT: Often when people request assistance to die, there is obviously a question around their capacity to make that decision. In your travels and interviews and speaking to people, as a prelude to the next question, I believe I have seen doctors give futile treatment at the request of patients, even though they know that it is completely futile. Are any questions raised around the capacity to make those decisions by the patient? On the one hand, when they say they want to take a treatment that will end their life, we question their capacity, yet futility of treatment is there as well. Does a GP or specialist, in your experience, ever think that these people are not capable of making the decision to have the treatment?

Mr DENTON: I have not had that direct experience, no, but it does get back to what I was saying earlier—that we start from a position of implied capacity. You question capacity if that question arises. I think the whole business of futility of treatment is another thing that lies at the heart of this. I think it is both the admirable thing about the medical profession and it is, unfortunately, a blunt instrument. This is why I have some respect and also empathy for doctors. There are machines built to keep people going. I think that what this and other conversations around these issues is beginning to raise within the medical profession is a serious debate about “Is that all we are here for?” I have spoken to a number of doctors—Atul Gawande, who wrote the book *Being Mortal*—and they all talk about the same thing, which is when they are trained, one of the first things they do in their training is they cut up cadavers. That process desensitises them to the idea that these are people. I am not suggesting that doctors do not see patients as people but, in fact, they are trained. I think I understand why. If you are too emotional with your patients, you are not going to be able to sometimes treat them in the way you should. I think a balance needs to be struck, which is why I talked about patient-directed care, where doctors see their patients more as patients.

I would say one of the most disturbing things that I have encountered in my explorations and my conversations, including with the very excellent palliative care staff here at St Vincent’s in Sydney, was what I felt was people who were so used to seeing death that they did not actually see the person dying. I say that very advisedly because I have great admiration for the people I met in palliative care. To hear the senior palliative care physician here in Sydney, Dr Richard Chye, who I followed around—he is an extraordinary man and a gifted teacher—basically say, “Everyone I spoke to at St Vincent’s agreed with two things. One is that there were patients whose suffering they could not help—not many but they existed. The second is that there have been some terrible deaths that they wish they could have done more for. Everyone, even the majority who oppose these laws, admitted that.” So as I explored this with Dr Chye. I said, “What do you do with those patients you cannot help?” He said, “I will help them to live with their pain.” I said, “To whose benefit is somebody like that being kept alive?” And his answer was, “I think it is of some benefit to the family.” I felt that was, with respect to Dr Chye, all about the doctor and not about the patient. I think that is a significant issue.

I know you have to wind up, but one of the elephants in the room in this conversation is a law that currently allows doctors to impose their personal belief systems. I have no issue with this belief; I just have issue with the law that allows them to impose that belief on others. There are doctors whose view of the world informs them that suffering is part of the rite of passage as you die. Of course, they are welcome to that belief, but the law currently gives them carte blanche to decide how much medication they give to a patient as they die. If that doctor’s or that institution’s core belief is that you do not assist someone to die and, what is more, that suffering is part of the deal, that is tough for that patient. One of the people I interviewed in the course of my research was Professor Alex Broom, a professor of sociology at New South Wales University. He spent six months in a Catholic hospice observing what was going on. This was some years before this debate flowered in Australia. He observed in detail quite a disturbing level of disconnect between the values of that

institution and what the patients wanted. Basically, as he put it, the important rites of passage that were important to that institution were mandating a way of dying which those patients did not necessarily want. To me, it is probably the most disturbing thing at the heart of this. There is now considerable testimony from patients within palliative care who died long and terrible deaths. It really bothers me that our law, without any question or scrutiny, allows doctors to choose exactly how they medicate those patients. They may well have a core belief that suffering is part of the deal. I think that is wrong

The CHAIR: Thank you very much, Mr Denton, for your evidence before the committee today. We really appreciate you taking the time to talk to us.

A transcript of this hearing will be forwarded to you for correction of transcription errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of what you said cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence. We will write to you with anything taken on notice at the hearing. I want to thank you again for your evidence and for the submission you have made to the inquiry.

Mr DENTON: Thank you very much. I get the sense that you have said that only a couple of times before.

The CHAIR: I have nearly learnt it off by heart—not quite.

Mr DENTON: I have really appreciated the opportunity and, Mr Goiran—have I got your surname correct?

Hon NICK GOIRAN: Yes.

Mr DENTON: I particularly appreciated the line of questioning. I am a great believer that the only way this gets properly done—written as legislation—is for there to be full debate. I will very carefully look at the submission you have directed me to and I will be happy to respond.

Hon NICK GOIRAN: Many thanks.

The CHAIR: Thank you very much.

Hon ROBIN CHAPPLE: And from a rejuvenated Mr Chapple, thank you very much indeed.

Mr DENTON: Thank you very much, old man—I mean, Mr Chapple!

Hearing concluded at 5.08 pm
