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 ONE

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 9.02 am

Dr PHILIP NITSCHKE
Director, Exit International, examined:

The CHAIR: Thanks for joining us this morning. I am going to read an opening statement and then we will move ahead with the hearing, if that is all right.

Dr NITSCHKE: That is fine.

The CHAIR: 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. I am the chair of the joint select committee. We have with us Hon Dr Sally Talbot; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; and Hon Robin Chapple. The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in WA and to highlight any gaps that may exist. You have agreed to provide evidence to the committee. Your evidence is protected by parliamentary privilege in Western Australia and protected by uniform defamation laws in Australia against actions and defamation. Please note these protections do not apply to anything that you may say outside of today's proceedings. It is important that you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. The audio-visual recording will be available on the committee's website following the hearing. Before we begin, do you have any questions about your attendance today?

Dr NITSCHKE: No, I think that is very clear, thank you.

The CHAIR: Good. Before we ask our questions, did you want to make a brief opening statement for the committee?

Dr NITSCHKE: Yes, I will make a brief statement. I noticed in your introduction that the purpose is to address or close any shortfalls that may be necessary under the existing legislation of Western Australia on end-of-life choices. I would like to talk about that for a few minutes and then will allow any questions that the honourable members might wish to address to me.

The first point I would make is that it is a very necessary decision to look and review the situation because Western Australia has some of the most draconian laws in the western world for the crime of assisting a suicide. Suicide is not a crime, yet the punishment in Western Australia can be the most savage in the western world. The possible penalties can be up to life imprisonment. That, of course, is an anomaly, where helping someone to do something that is lawful—suicide—attracts a penalty. There is no other example in law and that is a situation that needs change. It is very timely that such a review is being held. I think that some of the suggestions that have been made about how to better deal with end-of-life choices are important to look at and to learn from. One of the reasons that I placed a submission when I heard of this inquiry going ahead was because I have some unique experiences under the world-first legislation in the Northern Territory, which was the Rights of the Terminally III Act that came in in 1996. It was spearheaded by, I think, a visionary politician, Marshall Perron, who I understand you will be hearing from. He saw to make a change 20 years ago, and in the Northern Territory briefly we had that change where a piece of legislation allowed a terminally III person to get help from a doctor to die. I was a doctor who was working in that

situation. I supported the move and four of my seriously and terminally ill patients were helped to die. I saw the benefits of such legislation for not only the people who were able to benefit from it the four terminally ill people—but, of course, the whole community in the Northern Territory and I think the rest of Australia, who were watching closely. I was bitterly disappointed with the overturning of that legislation some eight months later. Having said that, there were problems with this legislation. I do not want to gild over some of the difficulties that were built into such legislation. If the Western Australian Parliament considers laws that may in some way parallel the rights of the terminally ill experience, it is important, I think, to learn from the difficulties and problems that we experienced. I will say a few words about that even though it is a long, long time ago. We have to also put it in the context of the day. This was, of course, the world's first legislation—that is how progressive it was. People often say that the territory is not known for progressive legislation on anything usually, but on this rare occasion the territory led the world and I was very proud to be part of that. But, as I said, there were problems. Marshall Perron foresaw some of those problems when he said—I remember asking him and talking to him about it before the vote was taken in the territory Parliament. He said he did not want sick people having to jump through hoops—his words. Of course, what we got in that piece of legislation, that Rights of the Terminally III Act, was a piece of legislation that made very sick people jump through hoops. When the law passed, I found myself dragging very sick people—in the first case, Bob Dent—from doctor to doctor to get the signatures necessary to demonstrate eligibility to die. The irony of that was not missed on people like Bob Dent who was so sick, yet he said, "I have to qualify to be eligible to die." I felt cruel having to drag him around to make him satisfy those onerous restrictions of that law. I saw the need for safeguards, but they were particularly difficult ones to comply with.

Since that time, another 20 years have gone by and we have seen effort after effort to bring in similar legislation in the various states and territories of Australia, including Western Australia, and they have all failed. I suppose people have learnt from that, in particular people seeking legislative change, that there needs to be perhaps even tougher laws so that they actually pass the parliamentary process. We have seen a recent passage in Victoria of legislation after 20 years. But with the increasing severity of the safeguards, my argument is that we now have pieces of legislation as morals, which are not only safe, they are so safe as to be almost unworkable. I have indicated that I believe the Victorian law, which will come in next year, is probably the world's most unworkable piece of legislation, certainly from the point of view of people wishing to participate in it. I would first of all make that point that I believe that there is definitely a need for change in Western Australia, but following along that strategy of making an extremely safe piece of legislation with many safeguards means, in fact, that you might end up with a model that really does not serve the interests of people who are seeking help to die. You can see some of these problems because when you start trying to codify—that is, set up the conditions under which a person can get help to die, and make those conditions very, very clear and strict—then of course there will be argument about whether or not people qualify. Then you have people say, "Well, I'm not quite terminal. What does terminal mean? Do I have to be able to say I'm going to die in this time or that time? Who's going to assess this?" Invariably it comes back down to the medical profession who act as judge here and effectively decide if a person gets the right to die, whether they qualified to die or not. That is not a position that fits very comfortably with many medical professionals. These are some of the issues. What qualifies? Do you have to be terminal? What is wrong with chronic suffering as a reason for wanting to die? What about the person who has motor neurone disease? Terminal, yes, but very hard to exactly define when a person is about to die. We can see many examples of people with motor neurone disease who have lived for years. Are they eligible or should they not be included?

What has happened where we have seen laws change and last longer than we saw in the Northern Territory, such as places like Holland, where I am now a resident, is that over the years people realised that the onerous restrictions cause difficulty and, of course, there is an erosion or a change to those requirements. We have seen changes here, first of all, to the age of eligibility, and then the nature of the condition and the nature of suffering that entitles a victim to make use of these laws. The rest of the world says, "That's an example of the slippery slope, the fact that we are seeing populations say, 'These laws don't really serve what people want.'" I think, quite correctly, we have seen a change and a modification of those laws. Rather than go through that process, I would urge the Western Australian Parliament to consider the fact that there will be this pressure to erode these laws—I do not think erosion is a good word, but to modify the laws to better serve the broader interests of the people. As time moves on in these 20 years, we are seeing a growing clamour for people to say, "Look, I want this option myself." In other words, we are seeing it finally coming to the point where people are saying, "This is not just some medical privilege for the very sick to be judged by a panel of doctors, but this is a fundamental human right." In the history of this issue with countries that have had 20 years or so experience with such laws, such as here, the question is now: is it a right or not for an elderly person to simply say, "If I want these drugs, I should be provided with them"? In other words, we are seeing a change from it being considered not just as a medical privilege for the seriously ill who qualify, but as a basic human right. That has been illustrated—and I will finish with this example in my general opening statement—with the circumstances surrounding the very prominent Western Australian, the emeritus Professor David William Goodall, who many of you will know because two years ago Edith Cowan University decided he was too old to have his office and they tried to stop him coming to work. He was, after all, 102 then. As you may know, he actually was given an office, not in the same university, but eventually there was quite a bit of publicity. You may have seen him recently on the ABC television reflecting on his 104th birthday and saying in that interview that he was a strong supporter of legislative change for voluntary euthanasia because he himself thought that this was important, and that received the publicity that it deserved. He also made the very, I think, telling comment that—they are his words— "It is my right as a citizen." He was talking about it being a right to get assistance to suicide. Perhaps what you do not know, though, is that Professor Goodall is now actively seeking help to die, and it is impossible under the Western Australian legislative model. With such savage penalties for assisting in WA, people who are close to Dr Goodall have to be very careful what they are doing, because anything that could be construed as assistance, could lead a person to be sitting in front of a Western Australian jury, with that jury reflecting on how you are going to be spending your next 10 years or longer in that state, so people are very careful. On reflection now, Dr Goodall has decided that the only way, other than becoming a latter day illegal drug importer, which he does not wish to do because he is a very law-abiding and prominent Western Australian citizen—that the only lawful option he has left is now to travel to Switzerland, where he has asked us, if we can, and yes, we have been able to organise a fast-tracked, if you like—an urgent referral to Switzerland, where the legislative model, which I would urge the Western Australian Parliament to consider, allows for a person to say, "Look, I've reached the end of my very productive life and now is the time to die. In other words, it's my right to have access to the best drugs." In Switzerland he will get the best drugs. Now we are trying to work out the logistics of trying to get this very important person through the very difficult journey, of course, some many thousands of kilometres away. Unfortunately, the only option left in a country like Australia is that a person will have to go and die in a strange place.

I think we can address these issues. I hope the Western Australian Parliament can look closely at this issue and at least bring in the most basic legislative reforms such as the rights of the terminally ill law or, heaven forbid, something as restrictive as the Victorian law, but ultimately see our way forward to bringing in an option that reflects the fact that this is a fundamental right—something more attuned to what we see in a country like Switzerland. I think that pretty well sums up my position. I am very able now to answer any questions that you may have and I welcome the opportunity to do so. Thank you.

The CHAIR: Thank you Dr Nitschke. I perhaps have a couple of questions and I am sure other members do too. Exit International says that it provides assistance and advice for people wishing to end their lives. Can you give us a bit more information about what assistance and advice that is?

Dr NITSCHKE: Yes, after the Northern Territory law collapsed with the pressure from the federal government and the decision that territory legislation was not to stand, of course, people did not stop coming along asking for help to take this step when they reached the point at which they felt their life should end, often in the context of serious suffering. So, what we decided to do, or what we found ourselves effectively having the only wa+s to recognise the fact that suicide is not illegal in Australia and so, of course, people were saying, "What can we do?" and the answer was: "You can end your own life", and that is a straightforward enough process provided you know exactly what you are doing. So, Exit became an organisation which gave information, so that people could take that step. That often meant telling them about the drugs that would work—not just might work; would work—and giving them details about how they might be obtained or, indeed, details of how they might travel to a country like Switzerland.

The CHAIR: Do you provide advice for people in terms of their legal obligations or those of family and friends around them?

Dr NITSCHKE: Yes, we do very much so, because, I mean, that is often, of course, the biggest source of concern, where people come along and say—this is a not uncommon scenario, where a person will say, "My husband is seriously ill and suffering badly and I am going to help him die. He is too sick to organise anything himself, so I am going to help." What we have to do and what we do do at that point is to say, "Look, we understand that that is the compassionate and loving thing to do, but it is not the lawful thing to do, so if you wish to take that step, go ahead, by all means, but be careful, because the trouble is that if you make a mistake and it becomes clear that you have in fact assisted the person you love to take that step to end their suffering, you could suffer serious legal consequence." That issue, especially in a place like Western Australia, is one which constantly is on our minds to make sure that people understand. It is often the case that people simply do not realise the problems they may get into if they do what they believe to be the right thing.

The CHAIR: Are you able to tell us how many members Exit has and how many members are residents of Western Australia?

Dr NITSCHKE: Membership, of course, is a fairly fluid number, because there is a lot of—I do not think "attrition" is necessarily the right word—but we have a lot of people joining and a lot of people die. All up, there are around 40 000 around the world. It is predominantly in North America. In Western Australia we have around about 1 000 people who are members or subscribers to our handbook, which is another way we get the information out, by constantly reviewing the best information for a person, in the absence of legislative change, to take this step.

[9.20 am]

The CHAIR: How many people has Exit assisted in Western Australia over the life of the organisation?

Dr NITSCHKE: That is a very hard question. If by "assistance" you mean giving information about how they might take this step of reliably and peacefully ending their lives themselves—that is, giving them information about what drugs are available, how to get those drugs, how to store them, how to test them and ultimately perhaps how to take them—it would be thousands. What we see more

and more, and I am sure you would be aware of this, is that, increasingly, elderly people say, "I want to be able have this choice myself. I do not want to have to go and ask permission. When I have decided that the time is now to die, I want to have that step, so I want to know that I have the best drugs." It is that quest for the best drugs, and in many cases hoping they will never need them, but drawing immense comfort from knowing that they have got the best of those drugs, the barbiturate Nembutal, in the cupboard with a shelf life of 20 years, hoping they will never need it, but drawing comfort and probably living longer because they have got that option in place. Is that helping them? I guess it is helping them have a happier life and probably a longer life, but is it helping them die? Well, for those to who take that step I guess the answer is yes, and that would be a lot, but it is very hard to quantify.

Hon ROBIN CHAPPLE: Dr Nitschke, Robin Chapple here. Do you consider in any way, shape or form that the operation of Exit International has been in some ways an impediment to legislative advances in the areas of voluntary assisted dying?

Dr NITSCHKE: Hello, Robin. Of course, I have certainly had that argument put to me. People say, "Why don't you just go away and shut up so we can bring in a piece of legislation, because what you are doing by talking like this and talking about a thing, a fundamental human right, rather than a medical option for the very sick, is that you are frightening the horses." In other words, they mean scaring the political process so that such laws do not pass. I do not actually think that is very sensible, because this is a debate which is going on around the world and I think it needs to be looked at in that context. If one's whole goal is to simply pass a piece of restrictive legislation, then of course one should never bring up the broader issues about what are the fundamental underpinning philosophical considerations we are talking about here. We are talking about human beings having the right to be able to dispose of that precious life that they have been given. If we simply said in that very restrictive framework of something that you provide to the terminally ill if they beg hard enough, I think that is a very narrow way of looking at the issue and I would not be prepared to shut up over that. Whether my comments have in some way slowed down the process, I think that is a rather easy way that those who have been campaigning for law reform in Australia for 20 years have a current convenient scapegoat there, because none of the laws have passed in various Parliaments, it is always good to blame someone, and one of the people who gets that blame occasionally is not just me, but Exit International.

Hon NICK GOIRAN: Dr Nitschke, we have never met before, but I have observed your work from afar and whilst we might not share the same view on this area, I have always respected your intellectual honesty, as has been demonstrated today in this morning's hearing. I do think it is useful that you have agreed to appear before the committee today, because I have found that in these debates people often look to overseas jurisdictions and seem to overlook the experience in our own country, in the Northern Territory. Were you the only doctor to have provided euthanasia in the Northern Territory during that period?

Dr NITSCHKE: Yes, I was. It was the world's first legislation and for a number of years I was the only doctor in the world who provided a legal lethal voluntary injection to a terminally ill person.

Hon NICK GOIRAN: I do not know if you have got a copy of your submission that you gave to the committee handy or not, but on page 2 of your submission you say to us —

In 1996–97, these safeguards were effective in ensuring that the four of my patients who used the *ROTI Act* in 1996–97 were all terminally ill, of sound mind, had their medical options fully explained, were over 18 years and so on.

Do you maintain to this day that your actions were lawful?

Dr NITSCHKE: Yes, I do. I mean, they were lawful under the Northern Territory Rights of the Terminally III Act and all of the four people who went through that arduous selection process demonstrated their eligibility.

Hon NICK GOIRAN: One of those patients was diagnosed with mycosis fungoides. One of the oncologists gave the patient's diagnosis as nine months, but a dermatologist and a local oncologist judged the patient was not terminally ill, and in the end I understand an orthopaedic surgeon certified that the ROTI act provisions for terminal illness had been complied with. Is that what you mean when you say that safeguards were effective and the patients were all terminally ill?

Dr NITSCHKE: Yes, that is what I mean. She had mycosis fungoides and I suppose if people look that up, they will realise what we are talking about here. Of course, that argument and debate over what constitutes a terminal illness is one that you will find yourself confronted with if you try to legislate on this issue and it is the one issue that has come up over and over again in the Victorian debate—what constitutes a terminal illness? In the case of Janet Mills, who had this disease, in the end, because there were diverse opinions, and you quoted one dermatologist there, but, of course, there was the other dermatologist who in the end said that she was terminally ill, but because it had to be a local specialist who did this, we had to find a local specialist, so there was debate amongst the dermatologists of Australia about the exact details of a terminal illness, but ultimately because we needed a Territory specialist, and there are not many, we got Stephen Badley, who was an orthopaedic surgeon, who, out of compassion said, "I cannot possibly stand to see this suffering going on any longer. I will sign it and take the heat", and by hell he took the heat.

Hon NICK GOIRAN: You will have to excuse my scepticism, Dr Nitschke. Prior to entering into Parliament I worked as a barrister and solicitor in this state and this particular case strikes me as a classic case of doctor shopping, but nevertheless, your experience, of course, is not limited to the Northern Territory. As you have mentioned to us, you are now residing in the Netherlands. Have you had much to do with The Last Wish Cooperative in the Netherlands?

Dr NITSCHKE: Yes, I do. I have quite a lot to do with the local groups here and certainly CLW—as you say, Last Wish—is an organisation I am very familiar with.

Hon NICK GOIRAN: I understand they claim to distribute a lethal powder to those who wish to suicide.

Dr NITSCHKE: Yes. This is a development which is sweeping across the world right now that you have drawn attention to. What has happened is that because there are some difficulties, certainly in the current climate, of obtaining the best end-of-life drug, which is the barbiturate Nembutal, people have been searching for a long time for an available alternative. Now, I suspect technology is going to bring this about pretty soon, and I should not perhaps at this point bring this in: that any legislation that is made might find itself swept away with technological change, because we are seeing changes around the world. The particular substance you are referring to is sodium azide, which is a substance that this group sees as being a cheap, available lethal salt that any person can obtain. It has come about at the same time as our organisation, Exit International, was looking at work done on the toxin for feral pigs in Queensland, which is sodium nitrite. Both of these available salts are receiving publicity and, indeed, are being sourced by people who are saying, "Look, I don't want to use it now, but I want this safety net in place", and this is a rather poor alternative to the much better Nembutal that people seek. The distribution of this salt—it is certainly a complication by CLW in the Netherlands—has drawn attention to this growing demand by ageing populations to have control over this most fundamental of life's decisions.

[9.30 am]

Hon ROBIN CHAPPLE: Just on sodium nitrite and sodium azide, you say that they are not as efficient as Nembutal.

Dr NITSCHKE: Yes.

Hon ROBIN CHAPPLE: What is the sort of difference in prognosis around their use?

Dr NITSCHKE: Sorry; I missed the actual question. They are not as efficient as Nembutal; they are not as peaceful as Nembutal. What was the specific question?

Hon ROBIN CHAPPLE: That is what I was trying to work out—why they are less efficient than Nembutal.

Dr NITSCHKE: They are not as peaceful. They are available, they are cheap, they store and they have not been considered, but they provide a death that is not as peaceful. The archetypal peaceful death that is provided by the barbiturate Nembutal is that you go to sleep very quickly, usually midsentence a few minutes after you take it—I have seen a lot of people take Nembutal—and then you go into a deep sleep and die, so you are dying asleep, and that for most people is what they seek. They seek this archetypal peaceful death while you are asleep.

Hon ROBIN CHAPPLE: Thank you.

Hon NICK GOIRAN: Dr Nitschke, I was interested in your comment on 2 September last year where you said —

With the wide, legal availability of this new drug, no one will bother with a restrictive euthanasia legislation that requires people close to death to obtain permission from a doctor to die. When the time is right, people craving a peaceful death, will simply take this new drug. No one will bother with the legislative safeguards in new proposed legislation, when this product becomes available.

In light of this, why have you told the committee in your submission that you have unique insights into how a carefully worded and construed end-of-life rights law can operate at a practical level? It all seems a bit redundant, does it not?

Dr NITSCHKE: It would seem redundant if the hope that was being held out by groups such as CLW for a drug like sodium azide were as forthcoming as they are. The stuff is not as good as it is being suggested as being, and nor is the Queensland pig poison. These are not as good as Nembutal, which I would hope a person might get if they satisfy the very strict criteria that hopefully the Western Australian Parliament brings in to a piece of legislation. I cannot anticipate the future. I am making some speculative predictions here and I did so when I put that statement out there. But there will be changes brought about by technology and designer drugs, and I think one needs to be aware of that when one spends time changing the law. But that basic fundamental, if you bring in a law with heavy restrictions—safeguards we call them—people will find it an onerous and difficult process. Even back as far as Bob Dent in 1996, he said to me after I dragged him around to see yet another doctor, "You know, if I had a bottle of that Nembutal in the cupboard, do you think I'd be off seeing a psychiatrist having my sanity tested?" The answer was, of course he would not. No-one goes through that process unless they are forced to do it, and that is the problem with legislation such as we saw in the Territory. It forces seriously ill people to satisfy requirements that they have no interest in complying with.

Hon NICK GOIRAN: Yes, indeed. I just want to unpack a little bit more about your comment in the submission about a carefully worded and construed end-of-life rights law. I know in an interview you did with the National Review online, you stated that your personal opinion was that if we believe there is a right to life, then we must accept that people have a right to dispose of that life whenever

they want, so all people qualify, including the depressed, the elderly bereaved, the troubled teen, and we should not erect artificial barriers in the way of subgroups who do not meet our criteria. Is that what you mean when you talk of a carefully worded and construed end-of-life rights law?

Dr NITSCHKE: We are talking about legislation and comparing it, I suppose, with the philosophical underpinnings of a person's beliefs. Realistically, the belief there is really a restatement of Thomas Szaz's principle that suicide is a fundamental human right and one that society has no moral right to interfere with. That is not a new idea; go back as far as Friedrich Nietzsche and the philosophers who have argued this way—that this is a fundamental human right. Precious life, precious gift of life, but what gift is it if you cannot give it away? That is all I am saying there. Now, the question is: who qualifies or who should have the ability to give away that life? I would argue, every rational adult.

That is my philosophical position, but I am also a realist. I know you are not about to pass a law that in some way enshrines that philosophical principle, so what I am saying is; let us look at the worst cases of people who suffer most under the existing situation and they, of course, are the terminally ill people suffering, who cannot get help from people who love them to have that peaceful death because Western Australian law simply says that if you help your husband or your wife to die by going across to Peru and bringing back a bottle of precious Nembutal and giving it to your husband or wife, you could be spending a decade in a Western Australian jail. That is something that has to change now and that is best done by carefully worded legislative change. Now, what do I believe or what do I want? I want to see a debate held about a "tired of life" argument such as we are seeing here in the Netherlands. Should every person over a certain age be issued with those drugs? That is where the debate will go. I am predicting that. It will happen even in Western Australia and other Australian states, because that is where the debate around the world is heading.

Hon NICK GOIRAN: Dr Nitschke, I just have one last question. During your opening remarks, you mentioned an individual. It is not important who the individual is, but you did say that if he travelled to Switzerland, he would have access to the best drugs. Can you just clarify for us what you mean by the "best drugs"? I think this is the committee's fifty-fourth public hearing and at least one of those public hearings was with Dignitas and they talked about helium at one point in time being used. Can you just clarify that for us?

Dr NITSCHKE: Dignitas, Ludwig Minelli and Silvan Luley, who are the current directors and who I know well, have had some time or exposure or experience, shall we say, using gas. They have decided, by and large, that it is not particularly productive or rewarding or something that people really want. That is one of the arguments. They have effectively resorted back to using the barbiturate sodium pentobarbital, which is Nembutal. But in the case of the good professor who was seeking to travel, now he will be going to a different organisation. There are two in Switzerland—one is in Basel and one is in Zurich—where the drug that will be used will be again sodium pentobarbital, or Nembutal. They often say that there are problems with the suggestion of using gas, especially in the European context, because of the history of the use of gas during the war in Europe.

Hon NICK GOIRAN: Dr Nitschke, have there been any complications with the use of Nembutal?

Dr NITSCHKE: They are rare and I guess you would have heard from Dignitas because they have almost more experience than anyone in the world over the use of that drug. Taken as a drink, orally—that is, by mouth—it is a very effective drug. To say that there have never been complications, though, there is an aphorism in medicine which I remember: never say never, because there are exceptions to everything, and there is always some example somewhere in the world where things did not go according to plan. I am sure that there are—of course, I have read of

some—experiences where the drug did not do exactly what it was supposed to do. On the other hand, as a predictable, reliable and peaceful way to end one's life, in all of my experience—I have had a lot now—I have never seen anything better. Of course, I have my own Nembutal; I have it in the cupboard, I know it is there, and I know that if I want to at any time have my peaceful death, I simply have to go to the cupboard, pour it into a glass, drink it down and I will have that archetypal peaceful death. Do I worry about the one in a very large number chance that something might go wrong? No, I do not. One simply has to make the decision that the very likely outcome of drinking that drug is peaceful death.

Hon NICK GOIRAN: Dr Nitschke, I will just conclude by thanking you for your evidence this morning and agreeing to appear. As I said at the outset, I respect your intellectual honesty in this debate.

Dr NITSCHKE: Thank you.

[9.40 am]

Hon COLIN HOLT: Good morning doctor, in your submission you talk about some safeguards that should be especially considered, one being, "The person must have exhausted all palliative care options acceptable to them." We have probably heard some evidence from palliative care specialists who, I think it is fair to say, would say they can give palliative care all the way to end of life. How would you define that statement of "exhausted all palliative care options acceptable to them"?

Dr NITSCHKE: Yes. I mean, it was a question that came up in the decision in the Northern Territory that there should be some way of knowing that the person knew that all of their medical options had been explored because palliative care was at embryonic speciality because there was a feeling that people should have at least talked to palliative care doctors to make sure that there were no other options that might alleviate the symptoms, if it was symptoms, that were driving them to take this final step of ending their lives. So I can see the reasons for doing it and I think it makes sense because it is part of informing a person who wants to take this important step that they have seen and understood all the available medical choices that are there. But as you have indicated in your question, of course you can be palliated to death. Some people would say, "Look, you don't need a legislative change on voluntary euthanasia; you just need better access to better palliative care", which is another way I think of saying, you just need to be given so much palliation that you do not really ever worry about dying because you will not know what is happening to you; in other words that you that you get extreme palliative care or as it is often called, terminal sedation. Look, this is a little bit of sophistry. I think the idea underpinning that comment though was that I think it is wise for people to be informed and I think that means that they need to know what is out there and then if they simply say, "Look, I don't like that; I don't like the idea of this particular form of, shall we say, palliative radiotherapy onto my cancer, I simply want now to say enough is enough and end my life." I think that has to be respected, in other words, an option acceptable to the patient.

Hon COLIN HOLT: Thank you.

Hon Dr SALLY TALBOT: Good morning Dr Nitschke. Can I ask you a couple of questions about assessment of capacity?

Dr NITSCHKE: Yes.

Hon Dr SALLY TALBOT: That was a deep sigh! Your sixth point is the person requesting the assistance must be of sound mind. We have heard from the psychiatrists that they are the only people who can do that assessment other than perhaps palliative care specialists or gerontologists. Can you give us your view about that?

Dr NITSCHKE: It is a very difficult question. As I indicated earlier, my fundamental belief is that a rational adult can have this choice and the question immediately comes, well what is rational and

what is sound mind. In other words, what we are talking about here is mental capacity, that is the ability to make decisions in your best interests. It does not mean though that you are excluded simply because you have got a mental illness because some people argue in the medical profession that mental illness means that you lack capacity. That is not true because you can have all sorts of mental illnesses and still have capacity to make decisions in your best interests. So the question is: What is the cut-off? When do you become so affected by a state of mental illness that you simply cannot act in your best interests? It is a very difficult issue, although I might point out that the assumption is that if you exist in society you have mental capacity. If you go and make a will, for example, the lawyer you talk to will make the decision that you have mental capacity. Decisions are made about this all the time. The assumption is that if you are in society you have mental capacity. If you lack it, existing legislation allows you to be taken off the street, certified and put in a locked psychiatric institution. A problem comes up because some people who do not like the idea of legislating change have argued that anyone who wants to die must have mental illness, therefore, lacks capacity. I see no easy answer. Referring a person for a compulsory psychiatric review was hated by the patients. That was the one assessment they hated. In the case of one of our patients dying of stomach cancer, he said, "I don't want to see the psychiatrists. He will say I'm depressed." Of course, given that he was dying a horrible death of stomach cancer in Darwin Hospital, he was not a happy man and he said, "But he will say I am depressed", and eventually we put it to the last day, the day that he decided to die. I said, "You fail the signature. You need a signature from a psychiatrist." So on the way to his little unit where he was going to die because you were not allow to die in hospital with that Northern Territory law, you had to get out of hospital and go home to die, we had to go via the psychiatrist to get the signature onto a piece of paper. Those sorts of ridiculous requirements when it was clear to everyone nursing him and knowing him this was a man who knew what he wanted but was he a depressed person? Of course he was depressed but that did not mean he lacked capacity. Ultimately, I see the answer to this—this is me speculating about the future—that this is going to be an innovative use of artificial intelligence where people are going to have things like their mental capacity checked by artificial intelligence. We are working on a project for a new machines here in the Netherlands/Osako where you do not get access to this machine to die unless you can pass the test and the test will be carried out by a computer. Otherwise, you are left with this idea that a doctor or a psychiatrist or a lawyer or someone else will have to make that decision.

Hon Dr SALLY TALBOT: My second question is about the opinion of the medical community, particularly doctors. It has been suggested to us particularly by one witness, who was a medical practitioner but opposed to voluntary assisted dying, that in jurisdictions where the measure is legal, doctors are refusing to participate because they hate it. Do have you a view about support for these kinds of measures in the medical profession?

Dr NITSCHKE: Yes. It has always been a problem in the sense that when the first suggestion was made in the Northern Territory by Marshall Perron, it was immediately very popular with the average Territorian but the medical association, my new association, because I had just decided to take on medicine, was very hostile and said there, "Look, there isn't going to be a doctor in Australia or in the Northern Territory who will have anything to do with such a law because it flies in the very face of what medicine is—that is how it was described—that it is an affront to medicine to even suggest that a person could get help from a doctor to die. Now I can see that issue. That of course, meant that the AMA in particular fought hard to have that law overturned and when it was overturned, it was not just the church; it was not just John Howard and politicians in Canberra like Kevin Andrews who saw the end of that law, it was actually the work behind the scenes of the medical profession to try to undermine the legislation. The reason doctors find it difficult—of

course, they do not all find it difficult because I found no issue with it as being part of care to of course provide that final help when a person asks for that at the end of their life. I saw that as being entirely consistent with good medical care and the Hippocratic oath. But I accept the statement that has been made that many doctors do not feel comfortable with it and, of course, in most legislatures there are opt-out clauses, as there are with abortion. A doctor does not have to be involved. What that will mean here in the Netherlands of course is that people will go and find another doctor and, of course, that is made somewhat easier by a requirement that a person is given that information about other choices. But the fact that some doctors do not wish to participate, I think, is certainly understandable and I would imagine that any draft legislation considered by the Western Australian Parliament would certainly incorporate that option by medical professionals not to be involved if you do go down that path of making assessment carried out by doctors in this process.

Hon Dr SALLY TALBOT: We know that the medical professional does administer terminal sedation to patients, would you describe that the arguments justify that as a piece of sophistry? Can you explain to the committee what you mean by that?

Dr NITSCHKE: Yes; it is because for a long time—in fact, is still the case in Australia—the only safest way for a doctor to provide a very sick patient with help to die is to administer terminal sedation because that gives the doctor an explanation for what they are doing. In other words, what they do of course is they start to administer usually an analgesic drug that is a pain drug like morphine, and they keep on administering it in increasing doses, saying, "Oh, it didn't work, we better increase it; oh the patient is still in pain, let's increase it again; that didn't work, let's increase it again." Eventually the patient dies and the doctor says, "Well, nothing to do with me; I was just administering good palliative care by controlling the pain." But of course, it has two big fundamental problems, one is that you must use as pain drug so morphine is the classic drug that is used. It is not a good drug to end life but it is the drug that has to be used if a doctor is using this as a way of providing them with a safe excuse for their action. The other thing is that it is a slow process because you have to look like you are trying to provide the morphine for the person's pain. Now that is not what is going on. What is going on is that the doctor is slowly increasing the morphine so that they can say that is what they are doing, knowing full well that what they are trying to do is to get to a dose high enough to kill the patient. Now that is also called slow euthanasia and it is sophistry because no-one is telling the truth. What is going on here is that a doctor is desperately trying to help someone but we are well aware of the fact that they cannot do it in the most humane way because that could put them into a Western Australian prison for the next 10 years.

[9.50 am]

Hon Dr SALLY TALBOT: Why do you describe morphine as not a good drug to end life?

Dr NITSCHKE: It is not a good drug. A drug which is useful during life and which provides a person with a reliable and peaceful death should do that—in other words, it should provide you with a reliable and peaceful death. The trouble with morphine is that it is an extremely variable drug in terms of its effect on individuals. You can take two people of the same age, height, weight and sex and give them the same dose of morphine and one will die of an overdose and one will not even know they have taken a drug. It is that variability, especially in the context of a person who is taking morphine, such as a person with serious pain associated with illness who becomes habituated to the drug. So it is a very difficult drug to know what a lethal dose is. In fact, in my handbook, I strongly advise people not to go down the morphine route. It is not uncommon for me to come to a person's bedside and for the patient, in the case of a person who is sick, pouring out a big pile of morphine tablets—MS Contin—that they have stockpiled and say, "I haven't told my doctor; look away, doctor, because I'm not taking my night time pain tablet for my cancer; haven't I got a lethal dose

here, doc?", and I look at the big pyramid of pills and I have to say to them, "Unfortunately, I don't know. You might have a lethal dose, but you might not." The problem with morphine is its variability. Nembutal does not have that variability. It is a much more predictable result, and of course what people want when they take this most final step is certainty.

Hon Dr SALLY TALBOT: My final question, doctor, is about the Victorian act. You have referred to it a couple of times in your evidence. Can you be more specific about what you see as the shortcomings of that act?

Dr NITSCHKE: Yes. Premier Andrews, when it was passed—I have nothing but the greatest admiration for the Victorian Parliament—I think showed some real innovation in getting that legislation through. We all in this room have watched 20 attempts to pass laws, and all of them failed, usually laws brought in as private members' bills and the like, huge debate, opposition from the churches et cetera, a lot of debate and often it closes in failure. What the Victorians did, I think very wisely and very strategically, was to set up the committee, which took evidence over a long period and drafted a very thorough report incorporating all views, and then that allowed the parliamentary process in a sense to say, look, we are looking at the distillation of all the intelligence and information that we have been able to gather. That, I think, is what allowed that law to pass. But of course it is simply a product of 20 years of failure, and to make sure that such a law, when it was debated and did actually pass, was extremely safe. You will all be aware, I am sure, that there was debate about terminal illness. What period defines a person's terminal status—is it six months, is it nine months? Oh, well, we have decided to make it even safer by making it six months. Most doctors involved watching that process closely just shrugged at that point, because that is an almost impossible decision to make. You just have no idea whether a person is going to live for six months or nine months. Yet to try and actually incorporate that, as they have done, into a legislative process is an example of making a particular law unworkable, in an attempt to satisfy and appease those who do not want this law to pass. That is a difficult process. I have got the greatest admiration that they were able to achieve it. But what they have got is a very cumbersome piece of legislation that I think will make the Northern Territory law look like a walk in the park—and that was hard enough. It is pragmatics. It is politics. I understand all that. But there are risks, too, because what you will get, and what the Victorians would get, I predict, is a law that very quickly comes under challenge from people saying this is inhumane and needs to be modified.

Hon ROBIN CHAPPLE: Dr Nitschke, in the deliberations we have had so far, we have heard from a number of people about self-administration or doctor-administration. The jury seems to be out on what is best or what is most—I do not want to use the word "efficient", but the better process for people at the end of life to go through.

Dr NITSCHKE: I did not like the idea as a doctor of going around and delivering—even though the legislation in Darwin said that I could—a lethal injection. I mean, I was passionate about this is right to have this choice, but I did not in a sense want to be the executioner. For that reason, I built a machine so that they could press the button. In other words, I was not trying to say I am not involved, because of course I put the needle in the vein and I loaded the drugs into the machine, but what I was trying to do there was say, "Look, the patient is initiating the process." In other words, it is patient-administered end of life as opposed to doctor-administered. That was important more to me, I suspect, than the patient, although it also got the doctor out of that immediate personal space and allowed others in. In the case of Bob Dent, Judy, his wife, was able to hold him as he died in her arms. This question about doctor-administered, I do not know too many doctors who would want to do this, even when they feel, like I do, passionately about it being a person's right. In a sense, with a bit of technology, one can make a system where a doctor does not have to administer the drug. A question comes up about whether the drugs are taken orally or not. Clearly,

if they are taken by mouth, the role of the doctor is pretty redundant anyway. I mean, they simply stand there and watch as the person stirs it with a teaspoon and then drinks it. It comes up more in the case of intravenous administration of drugs, but, even then, apart from the technical aspects of getting a needle into a vein, again there is no real need for a doctor to carry out the process. I think the role of the doctor, if anything, is this business of demonstrating whether a person has mental capacity, and then, of course, someone needs to make sure—it does not have to be a doctor—that the drugs that are being used are in fact pure and able to carry out this process.

Mr J.E. McGRATH: Dr Nitschke, you talked about the Victorian legislation and you had some concerns about the six-month time period. Most of us would agree that it is very difficult for doctors to actively predict how long a patient has to live, so you would expect that there would be some legal challenges to this. If a person wanted to challenge it under the Victorian legislation, how might they do that? Could they go around and find three specialists who say, "No; this person does only have five or six months to live"?

Dr NITSCHKE: I am not exactly sure how it is going to play out. I think what we will see is what we have seen in other countries, such as here, that there will be a number of pretty florid cases with people having a very difficult time and receiving a lot of publicity—of course the media will play an important part, I guess—where people are saying, "That is inhumane and there needs to be something done about this law that is forcing this person to wait until they pass the six-month or pass the nine-month or whatever the criterion is." So it will probably play out in the court of public attention rather than an actual legal challenge. You can see issues where people have tried to challenge this. I am thinking here in Canada where cases were brought urgently. There was also a situation in the UK where urgent cases were being brought by people who were dying. Of course this presents immense problems for the legal system. I think it will be a public media issue that will draw the broader public attention to the fact that this law has to be modified and made more humane.

The CHAIR: I have a question, Dr Nitschke. Are there circumstances in which Exit International would not assist someone?

[10.00 am]

Dr NITSCHKE: Yes, I can answer that. As I indicated, if I assist, I would say giving people access to accurate information so they can take this step and know that it will end their lives. But if a person is a child, they are excluded—we do not talk to children—and for a person who lacks mental capacity, now that assessment, as I have already talked about, is difficult. But, of course, if a person lacks mental capacity, it is actually not that hard to see—a person who really does not know what they are doing. Very occasionally, such people come our way—very occasionally. But it is rare. So, in answer to your question, yes, there are situations and certainly it has been the case, but it is not common.

Hon Dr SALLY TALBOT: Dr Nitschke, is it just a question of the time period involved in the act? Can you foresee any circumstances in which we might be able to legislate for people with dementia to access voluntary assisted dying?

Dr NITSCHKE: Dementia is one of the most difficult of issues. There are no easy answers to the dementia question, because a person who has serious dementia, of course, does lack mental capacity, so immediately they become excluded by most criteria. I would not have felt comfortable going to a person who had dementia and did not know what they were doing and then providing them with some form of lethal drug or injection. Of course, I would not feel comfortable with that because the argument goes, "Well, how do we know what they are thinking?" They might have suddenly decided to they wanted live on as they slipped into this demented state. There have been

attempts to try to deal with it through advance directives, through a written directive, which says, "If I get into this state, please, give me the drugs and help me to have them administered." But it does cause trouble. There have been some very florid and very public examples here in the Netherlands where that issue has come up and people have said, "This is not a satisfactory situation simply having an advance directive." I do not see any easy answer to it.

By and large, for the people who come out our way, saying, "Look, I've had an early diagnosis of dementia", a couple of things I point out are: it may be better to act earlier rather than later. Of course, for people who are caring for such individuals, as in the case of Shirley Justins, looking after Graham Wylie in Sydney, where he was slipping into dementia and she, as his loving wife, desperately tried to help him, found herself sitting in front of the New South Wales Supreme Court charged with assisting in the suicide of her husband. Then the eminent prosecutor Mark Tedeschi, QC, said, "Well, he had dementia, so that wasn't just assisting a suicide; that was murder because he didn't know what he was doing." So Shirley found herself charged with and ultimately convicted of, it turned out to be, manslaughter in the end. But there are real risks here, and when people start finding that this is a possible diagnosis, we have to tell them to think very carefully. Probably the wisest thing is to act earlier rather than later.

Hon ROBIN CHAPPLE: Thank you, Dr Nitschke. You obviously have concerns about time lines. In my legislation, I had a time line that was quite extensive, but it was very difficult to prove. You are saying that you feel that there are problems with the Victorian legislation about that six-month parameter. Can you provide any ideas or guidance on how to deal with this particular problem, which seems to be the bane of every piece of legislation that has ever been introduced?

Dr NITSCHKE: Yes, I think it may be wise just to omit the time line completely. I know that seems a little hard. What we are talking about here is suffering. Of course, you could say that a person who has severe diabetes can be suffering a lot and a person who has some of the chronic neurological conditions, such as multiple sclerosis and the like. To try to define these illnesses, which are often in the form of a waxing and waning, or remitting and remissions and exacerbation but are associated with a lot of suffering, as terminal is impossible. They are not often terminal illnesses, yet the person is going through a life that they do not want to live and they come to the point that at this point they wish now to have their lives ended. Trying to put a time line or a condition or to use the definition of "terminal", I understand why it is done; it is a way of trying to get legislation passed, because there are people who would find great difficulty accepting a piece of legislative change that said, "Well, you don't have to be terminal; you just have to be suffering in accordance with that person's subjective assessment." That can be extremely troublesome for some people who do not see any merit in such change at all; but, ultimately, I see that as being where it has to head.

In countries that have had legislation for a long time, that is generally where they have gone. They have tried to avoid the time line issue. They have tried to avoid statements such as "terminal" and used this idea of "chronic suffering" and, increasingly, as I have indicated, moved towards it simply being "patient request in the light of an informed decision", with the patient deciding that their life is no longer worth living. That is going to take a while to get to, I suspect, in Australia, but I think that is ultimately where the laws will head. I suppose you can perhaps short-circuit or at least cut off some of the arduous process over the next few years by having some progressive legislation in place, get it through the Western Australian Parliament, to sort of bypass some of these inevitable pieces of conflict which will come up over the coming years.

Hon ROBIN CHAPPLE: Further on that, Dr Nitschke, legislation is a very difficult thing to deal with. If we were to determine that people with a high level of suffering, you then come to that same

argument again: How do you determine suffering? Is it a pain level of one to 10? Who determines 10 and who determines suffering? Can you give us some thoughts around that?

Dr NITSCHKE: You really are pointing at the problems with what we would see as the medical model. The medical model, of course, is this model that has been used around the world. The laws try to set out to codify the exact conditions for eligibility, and those conditions are pretty nebulous, as indicated: things like "suffering"—well, who says so?—and other issues, "terminal". What is "terminal"? So it goes on. But, invariably, it is in the context of the medical model, and because it is in the context of the medical model, the arbiters of this process invariably are doctors. So you end up having to submit your case to a panel of doctors who decide whether or not you pass the test and are therefore eligible to die.

There are no easy answers to this question, because I, myself, believe that that medical model is doomed. I will be talking at a conference in Cape Town later this year that the medical model is finished. We have seen it evolve to a point where it cannot evolve any longer and we are moving towards this debate that is taking place in some countries that this is a fundamental human right and every person over a certain age should have access to these drugs. That is where I am predicting we will go. It is not of much relevance to the Western Australian Parliament right now. You are looking at passing a piece of medical model legislation, and coming along with that, as an inevitable part of it, is this incredibly difficult grab bag of concerns and considerations as you try to specify in detail each of these particular requirements to demonstrate eligibility, rather than throwing the whole lot out and saying, "Look, if a person is rational and an adult, then they can decide when the life they're living is no longer worth it." But of course they should have access to the best drug. But that is not going to happen now. What you have is a serious problem and I hope you deal with it in an insightful and innovative way—something like the Victorians have done—hopefully without quite as many of the onerous considerations and concerns that they have incorporated in their law.

The CHAIR: Thank you very much for joining us, Dr Nitschke. We have gone significantly over time. We really appreciate your time this morning.

Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of transcribing errors only. 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. Again, we really appreciate you taking the time to talk to us this morning, Dr Nitschke. Thank you.

Dr NITSCHKE: Thank you very much. I appreciate the opportunity to talk to the honourable members. It is almost dawn here so I will go back to bed.

Hearing concluded at 10.10 am
