

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, 2 MARCH 2018**

SESSION THREE

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 11.31 am**Professor MAX KAMIEN****Medical Practitioner/Emeritus Professor of General Practice, University of Western Australia, examined:****Dr ALIDA LANCÉE****Medical Practitioner, Doctors for Assisted Dying Choice, examined:****Dr IAN DAVID CATTO****Medical Practitioner, Doctors for Assisted Dying Choice, examined:**

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. Other committee members are Hon Dr Sally Talbot, John McGrath, Dr Jeannine Purdy, Hon Col Holt, Hon Nick Goiran, Reece Whitby and Hon Robin Chapple. 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 that 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 today's proceedings. I advise that the proceedings of this hearing will be broadcast within Parliament House and via the internet.

Would you please introduce yourself for the record?

Dr CATTO: I am Dr Ian Catto. I am a GP in Dunsborough.

Prof. KAMIEN: I am Max Kamien. I was professor of general practice at UWA and now I do country locums.

The CHAIR: Do you have any questions about your attendance here today?

The WITNESSES: No.

The CHAIR: Before we ask our questions, did any of you want to make a brief opening statement?

Dr LANCÉE: We represent our GPs' point of view on behalf of the group Doctors for Assisted Dying Choice and you heard our specialist colleagues on Monday afternoon and we concur with the evidence that they provided to the committee. We thank the committee for the thorough process they have initiated to identify and address the shortcomings of the current systems in place regarding end-of-life care choices. As GPs, we are specialists in holistic and patient-centred care and provide cradle-to-grave medical care for our patients. As doctors, we serve them to guide them through their healthcare options and follow their lead. The days of "doctors know best" have long gone. GPs know their terminally ill patients well and have known their families for many years. We have held their hands at the time of diagnosis and we hold their hand in their last days. We have experienced their journey with them. We witness their suffering firsthand. Maybe this is why 65 per cent of our GP colleagues support voluntary assisted dying choice and half would willingly provide service for their patients at their request, as indicated by a survey of the *Australian Doctor* journal in 2016. The Australian Nursing Federation also is another group of healthcare professionals at the coalface of end-of-life care and they also support voluntary assisted dying choice. We feel the need to express our feeling of helplessness and frustration with the current legal framework. The

current law prevents us from fulfilling our most important duty to a small number of our patients—to relieve their suffering at all times. We know that right now as we speak, people behind closed doors are experiencing unbearable suffering as a result of a terminal illness. Their cries for help to stop their suffering are denied. This inquiry will not hear these people, as the dying cannot represent themselves. This is why we speak on their behalf, as do well over 80 per cent of Western Australians when they indicate support for a voluntary assisted dying law. The medical profession community and religious groups have no role in deciding what treatment options are morally right for others. Those who find voluntary assisted dying not within their moral framework can choose not to be involved nor to request it; they are not affected. But they cannot deny others this choice; those who feel that no other option can stop this suffering. We urge the committee to ensure that any voluntary assisted dying bill will provide adequate safeguards; however, also avoid obstacles that may hinder access to voluntary assisted dying to those who need it most. The 68 criteria in the Victorian bill are excessive and create needless barriers to the most vulnerable, the terminally ill. Sufferers of neurodegenerative disorders endure a protracted course to their deaths. It is essential that these unfortunate people have access to medical systems to step out of their failing bodies when they feel that they have suffered enough. Emeritus Professor Max Kamien will illustrate end-of-life scenarios, followed by an outline of the benefits of the voluntary assisted dying laws for all Western Australians by Dr Ian Catto.

Prof. KAMIEN: I just want to talk about four examples briefly of my recent experience. The first is a lady who was 62 years of age when I first saw her and she had a limp. The limp turned out to be due to motor neurone disease. You just had the motor neurone people and I just talked to them about it as they went out. Gradually, the paralysis extended from her legs up into her arms and two years after diagnosis, she became what she called “a talking head”. She could move not a finger; she could just talk. The disease had literally stopped at the neck. She said to me, “Thank you for being my doctor for 30 years, and I know that when the time comes you will know what to do.” I do know what to do, but I do not have access to the drugs that would humanely do it. I also do not fancy spending my ninth decade in a jail and so basically I did not do it. She then tried to stop her life by withdrawing food and water and she did this several times and she only lasted three days, which is a pretty long time, actually without food and water. You are very dry and uncomfortable. She called her situation an ungodlike torture. She was a very staunch Catholic and had lost her Catholic faith. She said to me, “When I was going round in a gopher”—that was during the first year—“I should have taken my gopher and gone off the end of the jetty or driven into Lake Monger,” and she was sorry that she did not do it. She became increasingly short of breath and I was called. When I got to the house, a nurse was already there and the nurse informed us that she had just died. From my point of view I have failed that patient and I have failed her miserably, and I think about it a lot. She expected and deserved better of me and I did not give it to her.

Patient number two is her husband. He, too, was of strong Catholic faith and that had abated. Six weeks ago, he rang me and I could not understand what he was saying. He clearly had had a stroke; the stroke turned out to be due to a brain tumour, a highly malignant one, and he wanted to be nursed at home and he wanted me to look after him. He had only been there for three days. I would visit him every day and on the fourth day he had a fever and it was obvious that it was not going to be possible to nurse him at home and he went to palliative care and 14 hours later he was dead.

[11.40 am]

The third patient is a 65-year-old, very bright, medical physicist who started medical physics at one of our teaching hospitals. She had disseminated breast cancer with severe bone pain. She came to see me—I am not her doctor, but I knew her from the hospital—and she asked me, as she had asked several of her specialist colleagues, what was the best way to kill herself. She put her affairs in order

and she died at home alone. She ingested several concoctions that she had managed to acquire. She was in exactly the same position as Clive Deverall, who was the CEO of the Cancer Council and who killed himself. She, in my opinion, would have lasted a lot longer and been with her family a lot longer had she had access to assisted dying. She would have, I think, lasted at least six months—maybe longer—with the family, but she was not going to trust that because there was no assisted dying.

The fourth patient was a couple of years behind me at school. He was the top student in Western Australia and he was the swimming champion. He became an aeronautical physics professor. He also still holds the over-65 years 110-metre American championship. He developed a dreadful disease called supranuclear palsy. This is the top range of the Parkinson's-type disease. He has had it now for seven years. In the last four years, he cannot speak, he cannot use his iPad, and he cannot keep his eyes open most of the time. His brain is all right. He communicates; he can do that and he can do that [Witness made thumbs-up and thumbs-down signs]. His wife seems to know what he is thinking and talking about. He does not want to die. He wants to live. He believes that some cure will be found. He reads copiously about his condition. He thinks, because he is an astrophysicist, he can understand medical things, which he could not when he could talk to me. He does not want to die. Nobody wants to terminate his life. He wants to seek treatments like oxygen therapy and oxygen compression chambers. That is his business and he manages somehow to achieve that.

The purpose of these four stories is to set the broad scene. These major issues will have recurred, and have already occurred, in your inquiry and they have to do with patient autonomy. They have to do with the blind eye, the unspoken issues and practices at end-of-life care—the fear of a bad death resulting in a premature and a lonely death that could be prevented with adequate legislation. Doctors, especially family GPs, are denied the legal right to guarantee that we can provide compassionate care at the end of life to people who are being literally tortured and who want compassionate care.

The last thing is that assisted dying, as I have stated with my last patient, is a voluntary request. There is absolutely no intention, of the straw man argument, that this will lead to the death of people who do not want to die. Thank you.

The CHAIR: Thank you. Dr Catto.

Dr CATTO: It is widely acknowledged that palliative care has improved the quality of life and death for many people, yet there was considerable resistance to its introduction initially. Doctors for Assisted Dying Choice believe that carefully drafted legislation permitting voluntary assisted dying will similarly improve the welfare and deaths of some people who are dying. In addition, there will be benefits for the patients' loved ones and medical attendants. The Victorian inquiry into end-of-life choices found —

The evidence shows that simply knowing there is an option of assisted dying can be immensely beneficial to a person nearing the end of life, whether or not they choose to use it.

We fully concur. Benefiting a person at the end of life is what palliative care is all about.

The CHAIR: Thank you.

In relation to palliative care, we have heard evidence that palliative care probably cannot relieve the symptoms of around one to two per cent of patients. What is your view on that figure?

Prof. KAMIEN: The view is it depends who you talk to and it depends on whether you talk to them after they have had a couple of bottles of wine or before. The exact figure is irrelevant. If you talk to nurses who are there when it all happens, the figure is much higher than when you talk to

palliative care people. But, as I say, the figure is irrelevant because even if one person dies in agony, that is one person too many.

Hon NICK GOIRAN: Further to that, when you say “nurses”, you distinguish between nurses and palliative care people. Are nurses palliative care people?

Prof. KAMIEN: Yes, usually. I should say if you talk to palliative care doctors or palliative care nurses; there is a difference.

The CHAIR: I had a couple of questions relating to your examples. Would you say that all four individuals you referred to towards the end of their life had decision-making capacity?

Prof. KAMIEN: Their decision-making capacity is totally intact.

The CHAIR: I was interested in the young man who had to be moved to palliative care to die 14 hours later. Why was he not able to be nursed at home for that relatively short period?

Prof. KAMIEN: Because he had had catheterisation the night before which had failed and, as a result of that catheterisation, he had developed septicaemia.

The CHAIR: So he became very unwell, essentially?

Prof. KAMIEN: Yes.

The CHAIR: We have heard a lot of evidence around the practice of terminal sedation. Do you think this practice is well understood by the medical community?

Dr LANCÉE: Regarding terminal sedation, we make some general observations to start with in that terminal sedation is palliative care’s answer to refractory suffering at the end of life. The medical protocols for this terminal sedation are aimed to fit into the palliative care model of neither hastening nor prolonging death and are carefully and slowly titrated to appear to avoid hastening death. In practice, we know that these protocols are not effective and know that doctors regularly provide higher doses to ensure suffering is stopped as soon as possible, often hastening death in the process. The difference between terminal sedation and assisted dying is often not clear and it is carefully kept secret behind closed doors. This is the hidden practice and it is the elephant in the room, because medically assisted dying already happens. An anonymous survey by Neil et cetera in 2007 of 854 Australian doctors who work in end-of-life care showed that 35 per cent have already done exactly that. My personal experience is that, when talking to my colleagues in private behind closed doors, this is commonly practised. Currently, there is no information about when and where this practice takes place. There are no safeguards and no consent protocols, and nor is the practice universally offered.

Hon NICK GOIRAN: What practice is this that we are talking about?

The CHAIR: Terminal sedation.

Dr LANCÉE: Terminal sedation.

The CHAIR: Are you able to describe for the committee your understanding of what terminal sedation is?

Dr LANCÉE: Yes. Terminal sedation is when one aims to render a person unresponsive or sedated so they are, from an observer’s point of view, not experiencing their distress—in other words, by blunting their responses to their distress and rendering them unconscious. In theory, that sounds really great, but in practice there are a lot of problems associated with that theory.

[11.50 am]

The CHAIR: Can you elaborate on that?

Dr LANCÉE: Yes. There is no evidence that sedating someone actually stops their suffering. The Cochrane review looked at all terminal sedation literature available, and they had a conclusion drawn that there is insufficient evidence about the efficacy of terminal sedation in terms of a person's quality of life or symptom control. The Cochrane review is the gold standard of medical evidence collaboration where all the recent clinical trials and data are put together and a conclusion is drawn about whether that practice is good medicine or not.

The CHAIR: Do you think the current laws are adequate to protect doctors administering terminal sedation?

Dr LANCÉE: In terms of that question, we have compiled a response because there is some overlap between the answer to this question and the doctrine of double effect.

The CHAIR: Yes.

Dr LANCÉE: If I may read out the prepared response, please.

The CHAIR: Please do.

Dr LANCÉE: One member of our group—myself—has experienced firsthand that the law is not adequate. Legal advice has confirmed the subjective and grey nature of the current legal framework. The current law relies on the apparent intent of the medical practitioner. An observer may not know this intent and may misinterpret the medication provided to relieve symptoms as an attempt to hasten death. Drugs used to sedate and relieve pain may also reduce respiration. Once this observer has this interpretation, they can report the death to the police. They would spark a murder investigation and charge. Only during the court proceeding would a doctor be able to use the doctrine of double effect as a defence. The palliative care framework of terminal sedation using the slowly titrated dosing regime only serves the purpose of safeguarding the doctor from this potential misinterpretation. Neither the dying person nor their loved ones are served by this slow approach. Legal protection for doctors would allow less fear of prosecution and more appropriate dosing for severe end-of-life symptoms for their dying patients. A person with end-stage organ failure who relies on their central respiratory drive to stay alive may require only very small doses of sedatives for this drive to be interrupted and for death to follow. In those cases, the act of terminal sedation is indistinguishable from voluntary assisted dying. A very fragile person with end-stage organ failure will likely succumb as soon as a low-dose sedation medication is commenced. This is our experience.

Observational studies about terminal sedation in cancer patients have shown that respiration and circulatory suppression occurred in 20 per cent and was fatal in four per cent. This percentage is likely much higher in those with end-stage major organ failure. On the other hand, for a young person with healthy lungs and heart who is dying from cancer and experiencing intractable suffering, terminal sedation may be protracted. These persons may lie unconscious for weeks before they die from dehydration. This is extremely distressing for witnessing loved ones.

We are proposing a possible solution regarding the current legal uncertainty, with regard mainly to control symptoms when death is imminent. The current Criminal Code could be amended to exempt a medical practitioner who acts under specific request of the patient to administer optional medication dosages to control symptoms even if this may hasten death. An appropriate consent would need to be obtained and recorded in medical records. Similarly, advance health directives could allow a person to state that they wish for all treatment aimed to relieve their suffering, even if this treatment also potentially hastens their death.

That is where we stand on the legal aspects of terminal sedation.

Hon NICK GOIRAN: Dr Lancée, you mentioned that only in court proceedings would a doctor be able to use the doctrine of double effect defence.

Dr LANCÉE: Yes.

Hon NICK GOIRAN: Would the doctor not be able to raise that in an investigation rather than in court proceedings?

Dr LANCÉE: During the investigation, the person who is investigating is a police officer. They do not have necessary expertise regarding medical management of that patient. It would be unlikely that a police officer would take the word of a doctor saying, “I only wanted to help to stop her suffering.”

Hon NICK GOIRAN: So it would not be possible for the doctor to raise that during the investigation?

Dr LANCÉE: They could raise it, but my legal advice is that that is not necessarily going to create no prosecution.

Hon NICK GOIRAN: Assuming there was a charge laid, would it be possible for the doctor to raise it with the prosecutor prior to court proceedings?

Dr LANCÉE: Again, they could raise it, but there is no guarantee that that would stop a charge being laid and a court proceeding to follow.

Hon NICK GOIRAN: You mentioned that this is based on legal advice. Does that legal advice tell you in what section this defence exists?

Dr LANCÉE: You have evidence from Mr Johnson Kitto who explains that.

Hon NICK GOIRAN: Are you saying that on the public record with the committee, there is an outline of the section that sets out the defence of the doctrine of double effect?

Dr LANCÉE: He states specifically that that defence is only there after a charge has been laid, yes. You can refer to Mr Johnson Kitto’s submission for that.

Hon NICK GOIRAN: If we have further questions on that, would you be happy for us to come back to you?

Dr LANCÉE: Absolutely.

Hon NICK GOIRAN: Thanks.

The CHAIR: In your view, do you think an instance of terminal sedation should be formally noted on a patient’s medical record?

Dr CATTO: An instance of terminal sedation should definitely be recorded in a patient’s notes. What is surprising is that this has not been a requirement to date but that is consistent with its milieu, which is, the less said about it, the better. Documented information should include: the date that terminal sedation is initiated; the reasons for it; the method, including which medications; the expected outcome and an estimate of when this is likely to occur—family and friends would appreciate this; contingency plans should something go wrong; and informed consent obtained from who and when.

The CHAIR: In your submission, you indicate that some doctors practise slow assisted dying and others rapid assisted dying. Can you elaborate on what you mean by this, please?

Dr LANCÉE: Yes. We actually did not say slow or rapid assisted dying; we said slow or rapid terminal sedation.

The CHAIR: Okay; apologies.

Dr LANCÉE: Slow terminal sedation is the official slowly titrated dose regime that the palliative care profession has described, as I indicated. It is hardly a way to ensure that suffering is stopped as soon possible when a person is already dying and has severe refractory symptoms. Many medical and also nursing professionals recognise this problem and will give medication doses which are high

enough and quick enough to ensure that this suffering is stopped quickly, often with the understanding that this may also hasten death.

The CHAIR: Under the Coroners Act, a reportable death includes a death that occurs under anaesthetic. Would you consider a terminal sedation to be a reportable death?

Dr LANCÉE: As we conferred with our specialist colleagues on Monday, we feel that those two scenarios are totally unrelated. One is an unexpected death; the other is an expected death.

The CHAIR: Do you think the uncertainty around the legal framework that you have mentioned and the high use of opioids is contributing to the under-dosing of patients?

Dr LANCÉE: Absolutely.

The CHAIR: That would naturally result in extended pain and suffering.

Dr LANCÉE: Needless end-of-life suffering; that is why we are sitting here.

Hon ROBIN CHAPPLE: Earlier on, I am trying to remember who said it—it might have been Dr Alida Lancée—you said the Victorian legislation creates problems.

Hon NICK GOIRAN: Needless barriers.

Hon ROBIN CHAPPLE: Needless barriers; could you outline what those barriers are?

Dr LANCÉE: The barriers there, I will certainly take notice the specifics there, but in terms of eligibility criteria, I think the six-month prognosis is limiting for including all those that would benefit most from the law, and in terms of all the bureaucratic issues as well. Can I take that on notice and get back to you?

Hon ROBIN CHAPPLE: Yes, please do. We will put that on notice.

Mr R.R. WHITBY: I think the evidence you have given today is that, without a doubt, there is a form of voluntary assisted dying already occurring in which doctors are involved. How does this sit with the Hippocratic oath and the concept of “Do no harm”? If we did have such a law in Western Australia, would there be doctors who would be prepared to administer the dosage themselves? What should the law say about that?

Dr LANCÉE: Max, you are an expert on the Hippocratic oath. Are you able to comment?

[12.00 noon]

Prof. KAMIEN: The first thing is that the Hippocratic oath is 2 400 years old. We do not follow too many things that have happened, and since that time the idea of patient autonomy is now in the oath that students take, which is based on the Geneva oath. Patient autonomy is something new; it becomes an added factor within the oath. One of the oaths also talks about doctors looking after themselves, which I think is a bit excessive within an oath. But, if somebody is already dying, and you hasten death because they are dying in a very particularly nasty way, I cannot see that as really breaking an oath.

Mr R.R. WHITBY: So you are of the view that any law change would involve doctors administering lethal dosages or being otherwise involved in the patient’s death. You are saying that doctors should be involved in this process if we change the law. It should not be just up to self-administration by the patient.

Prof. KAMIEN: The patient makes the decision. The doctor makes the decision about whether they wish to be part of assisted dying or whether they do not wish to be part of assisted dying. The Hippocratic oath, which was, for its time, brilliant, has changed, and people’s deaths have changed, situations have changed, and even the oath that medical students take has changed.

Dr CATTO: Can I go back to a previous question? Is that allowed?

The CHAIR: Yes.

Dr CATTO: You were asking about whether current laws are adequate to protect doctors administering terminal sedation. I was trying to find the reference to our specialist colleagues' response. Just briefly, no, current laws are not adequate to protect doctors. We agree with the submission from Johnson Kitto. He has personally pointed out to me that section 259 of the Criminal Code is exculpatory in nature. What it offers is not an exemption from prosecution, but a defence in the event of prosecution. That is the section of the code.

Mr J.E. McGRATH: Further to the question that was asked by Mr Whitby, professor, I think the question was, if there is a change, would you prefer that the process was carried out by a doctor or a system where the patient could administer the drugs at home on their own?

Prof. KAMIEN: It depends on where the patient is at. The first two patients that I have described would be unable to administer the medication. If a patient can administer the medication and wished to do so, that would be their wish.

Mr J.E. McGRATH: Further to that, could there be any pitfalls in leaving that to a patient—a person who has got no skill in medical practice? Is there any risk that it might not work properly?

Prof. KAMIEN: It would be up to the patient to say whether they wanted a nurse or a doctor to be present. It would be up to the patient to discuss with the doctor whether there could be a fallback situation if it did not work. But from what I have seen of what happens in Europe, it works.

Dr LANCÉE: Can I add to that, regarding the option of self-administration versus physician injection? There are actually five points that we included for why we feel that both options should be available to a person. First and foremost is individual autonomy, that patients should be offered all options so they can decide for themselves. Secondly, in jurisdictions where both options are available, most people prefer the injection method. Medications for medically assisted dying are freely available for an injection, however nembutal is still not available, and that is the only medication that can safely and assuredly assure a peaceful passing. Self-administration actually requires a person to swallow 100 millilitres of a very bitter-tasting fluid, and they need to do so quickly, without gagging or vomiting, and some patients may fear that their disease progression may in fact prevent them from ingesting that, and they may take this medication sooner than if they also had an injection option available. Lastly, the Victorian bill indicates that an injection could be an option only if the medical practitioner was of the opinion that self-ingestion was physically impossible. This was a subjective matter where the medical practitioner needs to interpret, and it may not be clear. For example, if a person tells a doctor that they would gag from the bitter taste, does that then mean that that person can opt for an injection? It leaves, again, unclarity and uncertainty, and I think we really should ensure that patients are always the persons who make the decisions, not doctors.

Hon Dr SALLY TALBOT: Dr Lancée, can I take you back to your opening statement and just ask you about the figures that you quoted from a 2016 survey, which sounded to me to be slightly different to the figures the AMA have come up with?

Dr LANCÉE: These are general practitioners.

Hon Dr SALLY TALBOT: So it is a different survey?

Dr LANCÉE: It is a different survey.

Hon Dr SALLY TALBOT: Can you talk us through this one?

Dr LANCÉE: That is the pie graph of the survey, where 65 per cent have said they do support laws which will allow doctors to end the lives of terminally ill patients facing intolerable pain, and

65 per cent said yes, 32 per cent said no and, would you be willing to assist, and 49 per cent said yes, and have you had requests from patients, and 45 per cent said yes.

Hon Dr SALLY TALBOT: And that was a national survey?

Dr LANCÉE: This was a national survey done in 2016, yes.

Hon Dr SALLY TALBOT: Thank you. I just wanted to get that point of clarification.

Hon NICK GOIRAN: Dr Lancée, in response to the question from my colleague Mr McGrath you raised nembutal. I note that your submission also refers to it as being the gold standard. What are the complications with nembutal?

Dr LANCÉE: The complications—in terms of—well, the complication would be that it is very bitter and it is very difficult to self-ingest. Complications in terms of whether it has the outcome that the patient wishes, there is a potential that it may lead to a protracted uncertain duration that it takes from ingestion until death, and I think in Oregon there was one person who actually woke up again, so needed to have the injection as a backup to allow them to stop their suffering.

Hon NICK GOIRAN: I appreciate the frankness of your answer, so I ask: despite all of what you have just said, do you still maintain that it is the gold standard?

Dr LANCÉE: Absolutely; there is nothing else, no concoction that you can put together that is as able to guarantee a gradual peaceful passing for someone in terms of an orally ingestible form.

Hon NICK GOIRAN: When you say “guarantee”, obviously that is in the context of all those complications you have just been telling us.

Dr LANCÉE: There is one person out of, I think, 300 that ended up needing to have assistance as a backup. That is there. There is not surety, so we do advise the committee that medical backup is recommended.

Hon ROBIN CHAPPLE: Dr Lancée, when it comes to nembutal, obviously it is illegal, but people get it, bring it in and use it, but because of the nature of its illegality it can only be provided currently in the form of a digestible liquid. Could one make an observation or suggestion that, should nembutal be legal, it could be encapsulated, and taken that way?

[12.10 pm]

Dr LANCÉE: There is one medication that is used, and that is secobarbital, which is not pentobarbital, and that is also used in other jurisdictions. It is also a quick-acting barbiturate. The problem there is that a lot of people in the last phase of their life cannot swallow tablets or capsules, but they can ingest liquid.

Hon COLIN HOLT: The gold standard for oral ingestion or oral-assisted dying is nembutal. What about an injection? What is used then?

Dr LANCÉE: From my readings, the protocols are relatively similar across the world. One of them uses initially a small dose of midazolam, which is similarly used in sedation. After that, if the bystanders and the patient under a sedated state still indicate that they wish to proceed, they are provided with an anaesthetic medication called propofol, and after that they are given a muscle relaxant, usually a long-acting muscle relaxant like pancuronium.

Hon NICK GOIRAN: Further to that, Dr Lancée, what are the complications of that process?

Dr LANCÉE: The only thing that can happen that is unforeseen would be not being able to get venous access, meaning not being able to get a vein.

Hon NICK GOIRAN: That process is not considered a gold standard?

Dr LANCÉE: There are serious protocols, and certainly the protocols in place have different benefits and otherwise, but certainly my recommendation would be to adopt the protocol that has been used for the longest and has the most robust data about its efficacy.

Hon NICK GOIRAN: Which is what?

Dr LANCÉE: I do not know that. I have not researched it because I have not needed it.

Hon NICK GOIRAN: But you did indicate to us that nembutal is the gold standard. In my mind, when we talk gold, I think of the Olympic gold medals.

Dr LANCÉE: That is a medical term. In medical terms, sometimes there are several different options for a medication, which in some individuals may have different benefits to other individuals. There is no such thing for nembutal. There is only one thing that actually is used worldwide.

Hon NICK GOIRAN: So are we talking about multiple processes that might meet the gold standard, or is there only one process that meets the gold standard?

Dr LANCÉE: For oral ingestion, there is only one. In terms of injection therapy, there is no gold standard. There are several ways that may be applied, but in different jurisdictions, and recommended.

Hon NICK GOIRAN: That is fine. Thank you.

Mr J.E. McGRATH: Getting back to what you just said, doctor, the intravenous method, provided you have got the vein and everything, and you said there are three processes, how long would that take to have full effect on the patient?

Dr LANCÉE: Usually from what I have researched—again, I do not know from personal experience—they say that within 10 to 20 minutes the person has deceased.

The CHAIR: In relation to voluntary assisted dying, we have had evidence from the Chief Psychiatrist that if that legislative framework were to be introduced, mandatory assessment by a psychiatrist to assess capacity should be required in the legislation. What is your view on that?

Dr LANCÉE: Max, you are into capacity assessments and the like.

Prof. KAMIEN: I was once a psychiatrist.

Hon ROBIN CHAPPLE: Be wary of what you say on the public record!

Prof. KAMIEN: That was the standard joke in Perth and New South Wales! Most mental illness is dealt with by general practitioners. You only bring in a psychiatrist where your therapy is not going to work, or if the patient is in absolute extremis. I have spent much of the last two weeks with one patient, a young man who wants to kill himself. I cannot get adequate psychiatric care for that particular person. He had psychiatric care when he had money; now that he has got no money, the public service barely works. One of the things, the practical part of it, is to get a psychiatrist in. To find one would be very, very, very difficult. The second thing is it is relatively easy to diagnose depression. It is not rocket science. Most of the depression is diagnosed and treated by general practitioners. The third thing I would say is that general practitioners over time know about their patients. I mean, I am in my fifty-eighth year as a doctor and I am in my forty-fourth year as a doctor in Western Australia. I have had patients for all of those 44 years, over four generations in some families. So I know what is going on with those patients. I know that with one family—the family of the first patient that I quoted—if they come in and they have got a pain here, it is likely to be gallstones, because 18 of them have had gallstones. People who are depressed, you pick them up. The difference between generalism and specialism, apart from income, is that generalists see the patient over a long time. We see the moving picture. The specialist sees a snapshot. So calling in a

psychiatrist is a difficulty. For instance, this young man is psychotic. He has got irrational thoughts. He is very bright, and he keeps the irrational thoughts to himself, and the psychiatrists who see him say, “Well, you know, he’s not psychotic; he’s not psychotic on the basis of a depressive illness. He’s just in a very bad situational sense. He’s not really depressed. It’s just the situation.” My take on this man is that he is psychotic. His family’s take is that he is psychotic. He has now seen three different psychiatrists, and none of them, in my view, have even come up to the beginning of the formulation of what is really troubling him. I write long letters to them, and they read my long letters and they say, “Well, yes, but I still think my formulation is correct.” I have known this kid since he was born. I have probably spent the best part, if you added all the time together, it would be maybe several weeks. They have spent 20 minutes, and they would argue. I would think that in a country town, trying to get psychiatric help, you would have to do that by teleconference, which is a very unsatisfactory way of doing it. I do not think that psychiatrists really have a place. If you think the patient is really depressed and you are not getting anywhere and you want backup, yes, you would call in a psychiatrist, but not to testify that this patient is mentally capable of giving informed consent.

The CHAIR: We have had evidence from the Chief Psychiatrist also, and we explored this a bit further with him, because it is a higher bar than is currently set out for capacity for other medical and legal requirements. I do not want to misquote him, but the general sense of him was that because of the long relationship that GPs have, they could have a potential bias. Do you have a comment on that?

Dr LANCÉE: Can I make a comment on that?

The CHAIR: Yes.

Dr LANCÉE: I am going to again read something that I wrote before, in anticipation. Specific decision-making capacity assessment is carried out routinely by general practitioners anyway in terms of drafting their legal documents, or for the State Administrative Tribunal reporting. We certainly understand that the capacity to decide is not in itself related to poor memory, and that reasoning, in-character decisions and consistency, however, needs to be preserved. The people who know whether consistency and in-character decisions are present are the people who have a longitudinal relationship with that individual, not a person who sees them on a half-an-hour interview.

Prof. KAMIEN: Could I just add something?

The CHAIR: Yes, professor.

Prof. KAMIEN: I have been excluded from many panels such as this, and the reason given is that I know a great deal about rural medicine and a great deal about Aboriginal health, and, because I know so much, I will be biased, and people who maybe do not have that background of course come to it with an open mind, and therefore they are not going to be biased. That is open to question, too. I just think that that response is—I reject it completely.

[12.20 pm]

Hon NICK GOIRAN: To any one of the witnesses really: with respect to the legislation that exists in other jurisdictions, my recollection is that it does not mandate that there has to have been a significant relationship between the practitioner and the patient. In other words, the people who are performing the acts which are said to be safeguards could be brand-new practitioners to that particular patient. I am hearing from you that it is very important that there be a rapport between the doctor and the patient—is that right?

Dr LANCÉE: It is only in relation to whether a psychiatrist is more capable of providing the assessment for capacity to make decisions and for the presence or absence of clinical untreated depression.

The CHAIR: I just want to step back a bit to refusal of medical treatment. The refusal of medical treatment can include artificial hydration and nourishment by patients who are reliant on others for the necessities of life. In light of the Rossiter case, is this now clear for general practitioners, legally?

Dr LANCÉE: For GPs, I think we have always known that patient autonomy is paramount and that any person can refuse any intervention, including artificial hydration.

The CHAIR: In the circumstances of very end of life care, is refusal of medical treatment a consistent occurrence in your practice?

Dr LANCÉE: In terms of futile interventions?

The CHAIR: No. That is not futility; this is hydration.

Dr LANCÉE: Hydration intervention.

The CHAIR: Yes.

Dr LANCÉE: Certainly whenever a person has specifically requested either in an advance health directive or verbally that they not be artificially hydrated or fed, I think that that takes place, but that does not take place very often. We do see scenarios in nursing homes of people with severe dementia, lying in the foetal position, being force fed and hydrated for years. How they do that is they put a spoon on the back of their tongue, they put their finger on their throat to indicate the swallowing reflex. These people do not have hunger, they do not have thirst, but they continue to exist for years being force fed.

Dr CATTO: In my experience, people for whom palliative sedation is initiated are usually quite moribund and have minimal oral intake anyway, and so you initiate palliative sedation. They have already not been having much in the way of nutrition and hydration. In a disease with a longer trajectory, motor neurone disease for instance, it would seem incongruous to have terminal sedation and persisting hydration and nutrition running in parallel, unless the sedation was very light.

Prof. KAMIEN: Can I just give you a practical example. A friend of mine was called the singing dentist. He developed an oesophageal pouch—that is a pouch on the oesophagus—and food gets caught in it. You have terribly bad breath. It is very difficult to swallow. The operation is very difficult. It nearly always cuts the recurrent laryngeal nerve which is the nerve that goes to the voice box. If he had that operation, he would never sing again. The other thing is the operation has a mortality rate in itself which is, depending on who does it, quite high. He said, “If I can’t sing, I can’t speak properly, and if there is the possibility that something goes wrong and I finish up a vegetable, like my brother, I will not have that operation” and he ceased food for four months and he starved to death. He had a whole-page obituary in *The West*. When you talk to his family about him, they just break down—this was the most horrific thing not only for him, but for them. Yesterday, his older brother, who has been in a foetal position, unconscious, with severe dementia for eight years, died. He was being fed through a tube. He had no cognition whatsoever. His brain function was only at the brain stem level. It was absolutely horrific for his family. He was in a Jewish religious institution which does not condone any form of termination of life. It was absolutely horrific. He is being buried today at this particular time. This was a man who was the captain of the Australian debating team, the president of the East Perth Football Club and who set up a charity to make sure that old Aboriginal league football players had some sort of financial security. This man has just been lying there. I used to go to that aged-care place and I used to pass by; it was an absolutely tragic situation.

Hon ROBIN CHAPPLE: “Do not resuscitate”—we hear that is used on beds; it has been used for a long time in the medical profession. The rules have now changed. Usually, it is an advance care directive, something along those lines. Who makes the decision at different times? In the past we

have heard that it was basically the doctor or indeed a nurse that sometimes made that decision. Now with “do not resuscitate”, is it required that that is a doctor and the family making that decision, or is “do not resuscitate” still added to a patient’s chart by a relevant doctor?

Dr LANCÉE: I think that the table has totally turned there and that “do not resuscitate” is avoided like the plague because people are geared towards sustaining life and their on button is always on for resuscitation, particularly in major teaching hospitals. My father was admitted to a coronary care unit not so long ago and he brought with him his advance healthcare directive which indicated “do not resuscitate—no CPR”. This was in one of the private hospitals in Perth. The staff there were reluctant to accept that, saying, “We have our own protocols about this.” From firsthand experience, people do not look at advance health directives, and that needs to change.

Prof. KAMIEN: Could I add to that?

The CHAIR: Yes.

Prof. KAMIEN: Many of my patients—in fact all of my patients—have a health care directive. They give copies of it to their family. If that is available, usually in a hospital in an emergency department they will adhere to it except where you get younger doctors and they say, “This is the protocol.” This is what Alida was saying. “This is the protocol on how we treat this thing” and they are in a conflict between the advance care directive and the protocol. In the medical press recently there have been some cases of an Australian doctor talking about this and talking about the need for the education of younger doctors in hospitals as to how they deal with it.

The CHAIR: Is there a particular tension where those hospitals are run by religious institutions and those protocols are —

Prof. KAMIEN: Is there?

The CHAIR: Is there a particular tension where those hospitals are run by religious organisations where there is a difference —

Prof. KAMIEN: I do not know the answer to that.

Dr LANCÉE: My father’s case was in a Catholic-run hospital, yes.

Hon NICK GOIRAN: I know we are running short on time, so I just want to quickly take you to your submission. At page 11, you ask the committee to examine the ways to allow people with debilitating progressive conditions to choose to die with medical assistance when their suffering remains unbearable. Can you just explain to the committee what you mean by the term “debilitating progressive conditions”?

[12.30 pm]

Dr LANCÉE: The examples would be the type of people you have just heard about in terms of the motor neurone disease, cerebral palsy—people who have a disease trajectory that are not necessarily very rapidly declining but a much more prolonged, severe, reduced functioning for a long period. Do I have permission to put up a slide to indicate what those disease trajectories look like?

The CHAIR: Yes, please.

Mr J.E. McGRATH: While we are doing that, I am interested also if you could give us some idea of Parkinson’s disease compared to motor neurone disease. I have had people in my electorate say that Parkinson’s disease is very debilitating and at the end at some stages there is no quality of life at all.

Dr LANCÉE: Again, it is as neuro-degenerative disorder. It is where the brain stops telling the muscles what to do; again, they get stuck in their bodies. Their muscles are not paralysed, but they are rigid; they are stuck.

This slide is the commonly used disease trajectory where a function is one arm and time to death is the other. The cancer patients usually remain quite highly functioning right until their very end of life. People with organ failure such as respiratory disease or heart failure have a more gradual decline—intermittent severe exacerbation such as from a respiratory infection. They get to hospital, they get pick prepped up again —

Hon Dr SALLY TALBOT: Is that the —

Dr LANCÉE: That is what the dips are, yes. They get prepped up and they get a bit high functioning until gradually, of course, they die also. The blue line is the people we are talking about. They are the people who suffer the worst and the longest. If we in fact put in our legislation a time frame for prognosis, there may be people who would be falling in that group who do not have access to voluntary assisted dying.

Hon Dr SALLY TALBOT: Is the vertical axis the point of diagnosis?

Dr LANCÉE: I do not know. It was started; it was very likely that the point of diagnosis is much further down the line.

Hon Dr SALLY TALBOT: That is what I was wondering.

Dr LANCÉE: Yes. This is more a graphic description rather than an exact time frame. This is when you are diagnosed.

Hon Dr SALLY TALBOT: This is a widely disseminated study, is it; this is not something that —

Dr LANCÉE: No; I have not concocted this.

Hon Dr SALLY TALBOT: Can we look up the details for the background of the charts?

Dr LANCÉE: Absolutely, if you wish. This, I think, comes from the palliative care collaboration review, so I can provide that.

Hon Dr SALLY TALBOT: If you could.

Dr LANCÉE: Yes.

Hon NICK GOIRAN: Dr Lancée, just to follow that up and perhaps just following from my colleague, I concur with that slightly. That is a commonly used graph and I think the point you are making that the committee needs to consider is quite legitimate and fair. You are asking us to examine ways to allow people with debilitating progressive conditions to choose to die. Of course, time is a factor in that, as you have indicated.

I want to take you to another part of your submission—page 16—and there you include a fact sheet. The fact sheet there —

Dr LANCÉE: Was that included in this submission or my personal one, I cannot remember?

Hon NICK GOIRAN: That is a good question.

The CHAIR: There is one from Dr Lancée personally.

Hon NICK GOIRAN: I can give a submission number —

The CHAIR: Is it this one?

Hon NICK GOIRAN: — 402, yes; fact 6.

The CHAIR: Yes, that is Doctors for Assisted Dying.

Hon NICK GOIRAN: There with fact 6 you say that legalising assisted dying for the terminally ill does not lead to expansion of legal assisted dying for non-dying persons. The laws in the Netherlands and Belgium do not specify that the person should be terminally ill to qualify, but rather that they have unbearable suffering, a very different legislation to what is proposed for Australia. Any concerns raised from these jurisdictions are not relevant to the debate in Australia as the proposal for the current bill will specify that the person is terminally ill with a limited prognosis to be eligible.

Dr LANCÉE: Yes.

Hon NICK GOIRAN: I am just trying to rationalise those two positions.

Dr LANCÉE: Yes. Certainly when we are looking at the proposed criteria for inclusion—I will read out what we are suggesting the committee consider. Firstly, 18 years or over, legally capable of making decisions. Has a grievous and irremediably medical condition where the illness, disease and disability is serious, progressive and incurable; the patient has an advanced state of irreversible decline, so there is progress. Natural death due to a condition has become reasonably predictable in the near future. The patient is enduring intolerable physical and/or psychological suffering that cannot be relieved under conditions acceptable to the patient.

If I can put that into context. The current palliative care framework indicates that there are several trajectories that we look at where we emphasise certain interventions such as: are there continuing life-prolonging interventions or focussing more on palatable quality-of-life interventions? The cut-off there is the question that we ask ourselves: do you expect this person to die within the next 12 months? Or, the surprise question: would you be surprised? That certainly is a question that would be a reasonable area to look at, including that as in the guidelines—not necessarily in the legal framework—but in the guidelines of how the reasonably predictable in the near future prognosis would be included. If the answer to that question is “unsure” or if there is a no answer to that question—I do not expect this person to die—it may be that the person who is in that category has one of those neuro-degenerative disorders. In that case, we recommend the process is more thorough, where specialists are involved who are also able to determine whether the disease will progress and cause the person’s death in the foreseeable or predictable future.

I do not know anything about law or how that can be drafted, but I think there needs to be some way in which those people are not left out.

The CHAIR: Professor Kamien, all the doctors, I am interested in particular in Professor Kamien’s comment that most of your patients have advance health directives, when we have heard that the uptake of them is very, very low. What are you doing with your patients that means that so many of them have advance health directives?

Prof. KAMIEN: I am asking them. I just say, “Do you have an advance care directive? If you do not, you should have one. You can either get one and fill it in or you can go to your lawyer if you’ve got one, if you prefer that. People should know and your family should know what your particular wishes are.” As I get older, most of my patients are getting older too. Their fear is not dying; their fear is the process of dying. What is it going to be like? Am I going to choke to death? Am I going to be in severe pain? When I mention it to them, they go and get it. I must say that I have two demographics of patients; one is what you call middle class and the others are Aboriginal patients. Not one single Aboriginal patient has an advance care directive.

The CHAIR: I am conscious that we have gone over time. Do members have other questions for our witnesses?

Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the

transcript returned within 10 working days of 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 your evidence 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. Thank you all very much for your attendance today.

The WITNESSES: Thank you.

Hearing concluded at 12.39 pm
