

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
MONDAY, 26 FEBRUARY 2018**

SESSION FOUR

Members

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

Hearing commenced at 3.00 pm**Dr RICHARD LUGG****Member, Doctors for Assisted Dying Choice, examined:****Dr PETER GRATTAN BEAHAN****Member, Doctors for Assisted Dying Choice, examined:****Dr ROGER PATERSON****Psychiatrist, Member, Doctors for Assisted Dying Choice, examined:**

The CHAIR: Good afternoon. Thank you very much for joining us this afternoon. On behalf of the committee I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson and I am the chair of the joint select committee. I will introduce the members of the committee. We have Simon Millman; Hon Dr Sally Talbot; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin 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 you might say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. Do you have any questions about your appearance today?

The WITNESSES: No.

The CHAIR: Before we go to our specific questions, did you want to make a brief opening statement?

Dr LUGG: Yes, I would like to. On behalf of all of us, I would like to say it is an honour for us to have the opportunity to appear before what we regard as a most important parliamentary committee to explain our position on voluntary assisted dying to you and to answer your questions. Doctors for Assisted Dying Choice are a group of doctors from around Australia and New Zealand who feel frustrated by a traditional legal system that comes between us and our responsibility—our duty—to relieve the suffering of a small minority of patients at the end of life whose needs are currently not being met. We are here today to speak on behalf of that minority—the terminally ill who are battling unbearable suffering as their disease-ravaged bodies drag them down to sure and certain death. This disempowered minority cannot speak for themselves and yet they have the compassionate and sympathetic support of a vast majority of Australians. Over four adults in every five want something done about their plight. It seems that as modern medicine keeps more and more of us alive for longer and longer, there is a growing restiveness in the body politic—a growing realisation by more and more people that as they age, they face the real risk of becoming unwilling members of this most pitiable minority of all.

Some people have told you that we want the state to sanction the intentional killing of our patients. But their concerns are based on a false premise. None of us are in medicine for the purpose of killing our patients. Our duty is to help our patients—to help them get well when we can, but to relieve their suffering always. When we have terminally ill patients with unbearable suffering, when the effective relief options have narrowed down to just a single option, really, and when they request relief at any cost and are of sound mind, it is that relief and that relief alone that drives us to seek

reform of the law that traps our patients in their terminal suffering and stops us from helping them that last, final time. Yes, it is a relief of suffering that drives us, even when such relief can only come at the cost of shortening what little life is left. We are not in the business of killing our patients.

We actually think our Parliament has shown great compassion, as well as foresight, in setting up this joint select committee that we are appearing before today. We actually think the timing is pretty much perfect. We believe there is momentum for reform and that this committee has the ideal opportunity to recommend a law for voluntary assisted dying that is right for WA, takes account of our unique geography and provides the right safeguards, without shutting off access to the law by patients who need it most through overly prescriptive details and procedures. You have seen in our submission, and we know from your questions that you have been reading it, what we think this law should look like. We are here today to elaborate on our submission from the point of view of medical specialists and to answer your questions on the specifics of how that law should be framed. On Friday, our general practitioner colleagues will be giving you their take on these matters. Thank you, madam chair. I do know that Dr Peter Beahan to my right has a few general remarks he would like to make before we get down to the questions that you will ask.

Dr BEAHAN: I joined Doctors for Assisted Dying Choice in August last year. I joined out of conviction that its members were a group of the most compassionate doctors doing the best they could for patients in a neglected area of medicine. I soon realised I was not up to speed with the breadth of knowledge they had on the subject, so I sought to catch up by writing a paper on the case for voluntary assisted dying. This was done over a long period of time, during which I picked the best ideas I could from all members of the group. This document now represents the consolidated views of the group, covering all of the major points of argument. It also has some historical background that helps to put our present circumstances into a longer-term context. It is too long to read at this meeting, but we feel it would be very helpful indeed to members of the committee if I could be granted permission to table it for your information and consideration.

The CHAIR: We will take the document and the committee will make a decision about whether to accept it as a supplementary submission to your original submission. Thank you. Are there any further statements?

Dr LUGG: I have brought along three slides, which Jeannine has with her. Perhaps I should have asked whether, when the questions come up, I could have them shown.

The CHAIR: Yes, that is fine. We will move to palliative care. You have before you the questions that we sent through. A 2015 report of a survey of 1 800 patients of specialist palliative care services in Australia found that people receiving care from palliative care services frequently experienced high levels of pain, other symptoms and psychosocial concerns. Given your experience of the findings of the survey above, in your view is it likely that only one to two per cent of patients have refractory symptoms around the end of life?

Dr LUGG: The first thing I would like to say is that the report to which you are referring is actually a very important one, because it uses data collected at the University of Wollongong by Palliative Care Outcomes Collaboration, commonly known by its acronym PCOC. This is a commonwealth-funded program collecting data from healthcare workers and patients in palliative care services around the country. PCOC is the most authoritative and reliable source of data on palliative care in Australia. The report you have mentioned certainly shows that the level and frequency of symptoms of concern to patients greatly exceeds the estimates of one to two per cent that you have been given by certain witnesses. It is of interest that the corresponding author of the report is Tanya Pidgeon of the Cancer and Palliative Care Research and Evaluation Unit at the School of Surgery right here at the University of WA. Here is the first slide. This slide also is derived from data from the Palliative

Care Outcomes Collaboration. It comes from a May 2017 publication, also co-authored by Tanya Pidgeon—you can see her name down the bottom, as the third author from the left. These are interesting, because they are patient-rated severity scores of the key symptoms causing distress to palliative care patients in WA as they move into their terminal phase of decline. Most of these ratings are given only some two or three days, on average, before death.

The percentages shown are quite surprisingly high, and quite a lot of the moderate severity we can see, which is distressing to many patients, and I know members of our GP group will want to discuss some of those results with you when they appear on Friday, but today I just want to focus on the most severe symptoms. They are the ones highlighted in yellow. If we look at the severe and intractable pain down at the bottom right hand corner, we can see a figure of 2.2 per cent. That is the weighted average figure for all the patients in Western Australia from whom we have this rated data. It seems quite close, for example, to the figure of two per cent you were given back on 14 December by Dr Elissa Campbell, president of Palliative Care WA. Her figures were also based on PCOC data. Whereas Dr Campbell turned that two per cent figure around and claimed to you that palliative care is 98 per cent effective, you can see from this table just how wrong that statement was. If we just go up from the 2.2 figure, you will see 4.6 per cent of people are suffering very severe and debilitating fatigue; another 2.9 per cent have breathing problems, which means they are grasping the breath, basically, and so on up the table. Some people have more than one of these severe symptoms, so the figure of 12 per cent—it is going to be less than that because some people have more than one symptom. But we can see that it is going to be well over five per cent. There is 4.6 per cent in one group alone, 2.2 per cent and 2.9 per cent; it is going to go over five per cent. This is showing us that the number of patients who rate their own symptoms on the severe end of the scale in palliative care is somewhere between five and 10 per cent. I have gone to PCOC and spoken to their data manager, Sam Allingham—who is also one of the authors—and I have asked whether they can analyse the data to answer this question. This is a question that I want answered and I am sure your committee wants answered. I asked: what is the percentage of WA palliative care patients who enter their terminal phase with at least one symptom rated at the severe end of the scale? There is nothing in here that PCOC publishes that enables you to get that answer, but I am hopeful that they will be able to provide that answer to us. I have told them that when the answer is available, I would like to pass it on to this committee. However, as I said, we can see with a great deal of confidence that the figure is actually somewhere around five to 10 per cent. That is very consistent with other data that we hear of from other countries. That is my answer to question one.

[3.10 pm]

Hon NICK GOIRAN: Dr Lugg, can you just help me understand why you say five to 10 per cent?

Dr LUGG: If we add up all the severe symptoms provided by all the patients who participated, we see the total number of severe symptoms is 12 per cent. But we cannot say that 12 per cent of people are suffering from them because some of them undoubtedly will have more than one symptom, so some of them appear in the last column maybe two or three times. So it will not be 12 per cent; it will be less than that. But we can see that it will obviously be more than five per cent because 4.6 per cent alone are just suffering from severe debilitating fatigue. So if we add 2.2 per cent with pain, 2.9 per cent with breathing problems and so on, we can see it will go over five per cent. What I am saying to you is it is somewhere between five per cent and 10 per cent, and I hope that they will be able to give us a more precise figure.

¹ Correspondence from the witness clarifying this part of the transcript can be accessed on the committee webpage.”

Hon NICK GOIRAN: Looking at the line for fatigue, of 4.6 per cent, is the 4.6 not a percentage of all of the patients that were ranking fatigue, where 83.9 per cent said it was absent, 2.5 said it was mild, nine per cent said that it was moderate, and 4.6 per cent said it was severe?

Dr LUGG: Yes, that is correct.

Hon NICK GOIRAN: Again, can you just explain how you come to the conclusion that it is between five and 10 per cent?

Dr LUGG: Well, it is over 4.6 per cent and it is less 12 per cent.

Hon NICK GOIRAN: According to this data, 4.6 per cent of patients are saying that they have severe fatigue?

Dr LUGG: That is right.

Hon Dr SALLY TALBOT: Then you have to add up the ones who are having other symptoms, and that comes to 12 per cent. Dr Lugg is saying it is not 12 per cent, because some people will have two or three symptoms.

Hon NICK GOIRAN: It is not clear to me. I just would have thought if you read that table, it says that 4.6 per cent of patients who are ranking fatigue are saying it is severe.

Dr LUGG: What I would have liked to have brought to the committee is a figure that says how many have at least one of these severe symptoms. That is what I have asked PCOC to provide for us.

Hon NICK GOIRAN: Are they going to be in a position to do that?

Dr LUGG: He said he would take it away to discuss it with his people, but I do not think it can be that hard to do.

Mr J.E. McGRATH: Could you explain for us, please, when you say “at the beginning of the patient’s terminal phase”, when is that?

Dr LUGG: They identify four phases—the stable phase, the unstable phase and the deteriorating phase, and the last phase, obviously, is the terminal phase. These figures are ratings taken of patients who are at the beginning of their terminal phase.

Mr J.E. McGRATH: I would have expected those statistics to be higher.

Dr LUGG: Interestingly, some of them are not quite as high as they would have been in an earlier phase. We are only talking about severe symptoms. Moderate symptoms can also be very distressing, and if you throw them in, you can see that we are dealing with probably half—well, not half, but a very significant number.

The CHAIR: In reference to your submission, you have indicated that Australia ranks number two in the world on the quality-of-death index. Can you suggest any means by which more equitable access to palliative services might be secured?

Dr LUGG: Yes. I would like to make a few comments about that. Can I first say that not only do we rate number two in the world, but in terms of availability of appropriately trained staff capable of providing palliative care in hospitals or in the community, Australia actually ranks first, and in terms of affordability of palliative care, it ranks equal first. Within Australia, WA stands out, primarily because of the home-based palliative care service provided in the metropolitan area by Silver Chain. So we are actually a very good state within a very good nation. I think we can be quite sure that palliative care in WA is as good as anywhere in the world.

Coming to your question, there are two measures that we can think of that would improve equitable access. The first is obviously the extension of this very wonderful community-based service, which

is confined to the metropolitan area, to major country centres and then perhaps more into regional areas. The other thing that palliative care people always say is that patients come to them too late. It would be much better if people were encouraged to enter palliative care at an earlier stage of the trajectory of their illness.

The CHAIR: In your view, can access to quality of palliative care be maintained and improved in conjunction with the legal framework that provides for voluntary assisted dying?

Dr LUGG: Yes. Here again, the evidence from other jurisdictions is that palliative care services actually benefit when voluntary assisted dying is introduced. I think it opens up the dialogue for palliative care services—people feel more comfortable talking about their palliative needs. After all, palliative care will always remain the main provider of care. They will always look after the bulk of people. So I think historically it is of benefit to palliative care when a VAD option is available as well.

Hon NICK GOIRAN: Dr Lugg, you say that there is evidence from other jurisdictions that palliative care benefits when voluntary assisted dying is in place. What is voluntary assisted dying?

Dr LUGG: Voluntary assisted dying is an option provided in some jurisdictions, by law, permitting patients to ask an attending doctor to assist them in their last stages of their dying process in bringing forward their death at a time convenient to them.

Hon NICK GOIRAN: Have you practised medicine in one of those jurisdictions?

Dr LUGG: No, I have not.

Hon NICK GOIRAN: Are you able to point to us the evidence that you say in those jurisdictions, palliative care improves?

Dr LUGG: One thing that is really interesting is that of all the countries that have voluntary assisted dying legislation, all of them are in the top 11 countries out of, I think, 100 countries with a standard-of-death index. So they are all countries where palliative care is provided at a very high standard. The actual evidence that you are asking for, I can get for you; I do not have it at my fingertips.

[3.20 pm]

Hon NICK GOIRAN: Can we take that on notice, Madam Chair?

The CHAIR: Yes. We will follow up on that. I am going to move to the practice of terminal sedation. In your view, is the practice of terminal sedation well understood by medical practitioners in Western Australia?

Dr LUGG: If I can just make some opening remarks about the evidence behind the practice of terminal sedation, I notice that your footnote correctly identifies that death inevitably follows on placing a patient under terminal sedation. It is an important fact that you have recognised. In the absence of VAD legislation, terminal sedation is really palliative care's answer to the problem of end-of-life symptoms that are refractory to all the normal processes of medical management. I am sure it will always have a place, where there is no formal VAD request made, but VAD legislation, if it is available, in our view, offers a superior management option in those circumstances for those who wish to avail themselves of it. I would like to place on record at this stage our view that, because—we will be coming back to the reasons why VAD offers a superior patient management option from the patient's point of view—I would like to place on record our view that this is an important reason why a ban on doctors raising the option of VAD is not actually in the best interests of patients with unbearable suffering at the end of life. In any event, as doctors, I think we would consider it an unconscionable interference in the doctor–patient relationship. All treatment options should be on the table when doctors and patients are talking, and we think there should be no such ban.

Coming to the question of whether terminal sedation is well understood by medical practitioners in WA, it is a very secretive and undocumented process, and actually there are very good reasons for that. There are very good legal reasons that it is secretive and undocumented, because it helps protect the doctor if people do not know too much about it. I think it is not always well understood, but I know that the GP group that will be appearing on Friday has probably more direct knowledge of this, and I am sure they are going to have more to say about it.

The CHAIR: In your experience, is it always possible to determine whether a patient who has received terminal sedation still suffers with physical or psychological pain?

Dr LUGG: Actually, this is something I would like to toss to Peter. Dr Beahan is a long-time anaesthetist and he has expertise in the question that you have just asked, and I would like to invite him to deal with the question.

Dr BEAHAN: On the contrary, there is evidence that it is not possible. About 20 per cent of those who receive terminal sedation may experience some suffering. That is a soft figure; we do not really know because the patients cannot tell us. The general practitioner group whom you will meet on Friday will be able to describe better than I the hands-on experience. That may well be a different picture from the one given in the rather limited literature on the subject. Sedation is difficult to titrate as the patient may appear sedated while still able to experience some form of suffering, as in persistent pain, agitation, anxiety or awareness, without being able to move. This can even occur, rarely, under general anaesthesia, where additional inhalation of anaesthetics are used. Movement, or verbalisation, may be observed by family members in between visits by doctors. Agitation, delirium and difficulty with breathing may be observed from time to time. Respiratory and circulatory depression may occur and may be fatal, especially in more frail subjects. There may be an increase in blood pressure, heart rate and sweating, and pupillary changes. All these signs may indicate continuing stress. This risk of continued suffering would be more likely with lighter levels of sedation. Heavier sedation may be more effective, but also more likely to shorten life. By contrast, voluntary assisted dying in those who request it is quick, painless and certain. It also has other advantages, such as the ability of patients to speak to their loved ones, say their goodbyes and ease the process of letting go. These are all important. The dying process should not be as difficult as it is made to be. Patients do not fear death; they fear the process of dying, and with good reason.

The CHAIR: In your view, are the current laws adequate to protect doctors administering terminal sedation; and, if not, what needs to change?

Dr LUGG: I think the answer is that the current laws are not adequate to protect doctors. We have read the submission of Mr Johnson Kitto, and I have to say that we agree with what he has to say about the application of the Criminal Code. As a matter of fact, I had a conversation with Johnson Kitto, in which he personally pointed out to me that section 259 of the Criminal Code—which, if you look at the Victorian inquiry report, they say it holds up the beacon of double effect, and everything is sweet—but if you talk to Johnson Kitto, he says that all this is, is a provision that is what he calls exculpatory in nature. In other words, it does not offer any exemption from prosecution, but if you are prosecuted, it actually offers some sort of defence. But, actually, it is a conditional defence and the chief condition is a rather tough one. It is that the doctor's treatment has to be reasonable, having regard to the patient's state at the time and all the circumstances of the case. What does that mean? The answer, according to Johnson Kitto, is that it comes down to what the jury thinks. It seems to me pretty clear that that is not adequate. I know there are strong feelings about this matter from the GP group. One of our members actually has experienced firsthand the problems with this law. What we think is needed is a set of requirements, compliance with which would exempt a doctor from the homicide provisions of the Criminal Code. This

exemption could be placed in the Criminal Code itself, but it also could be placed in new legislation providing for advance care planning, for example, or for the introduction of VAD. In our view, and we are doctors after all, there will be advantages in having the area under the control of a health administration rather than a criminal justice administration. Can I add that—I know that we are coming up to the doctrine of double effect—what I have been saying now about terminal sedation would apply with equal force to questions about the doctrine of double effect.

The CHAIR: In your view, should an instance of terminal sedation be formally noted in a patient's medical record?

Dr LUGG: Yes. As your footnote correctly says, this does not happen now. If an exemption is to be put into law, it has to be subject to proper monitoring and review. I know the GP group will have more to say on that as well.

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

Dr LUGG: Yes, this is actually something that I know the GP group wants to talk about, but they did want us to make one clarification here, and, that is, that the submission was actually relating to slow and assisted terminal sedation. It was not meant to apply to assisted dying at all.

The CHAIR: Under the Coroners Act 1996, a reportable death includes a death that occurs during an anaesthetic. Should cases of terminal sedation be reported to the coroner?

Dr LUGG: Again, this is something that Dr Beahan in his role as an anaesthetist has firsthand experience of, and I would like him to answer that question.

Dr BEAHAN: There is no analogy whatsoever. In terminal sedation or voluntary assisted dying death is already inevitable, with no expectation of life in the future; whereas, a person who dies in association with anaesthesia was normally expected to make a full recovery and to enjoy life afterwards. Deaths related to anaesthesia are often unexpected and always unintended. Recovery is always the object. Recovery under terminal sedation is never the object. Let me make this point: doctors are skilled at identifying and recording the underlying cause of death and distinguishing it from the mode of dying. In the case of the terminally ill, the underlying cause of death in a dying patient is the patient's underlying illness. Medical assistance may be a mode of death but it is never the underlying cause of it. It must be made very clear that medical assistance with the dying process is not suicide on the part of the patient and is not murder on the part of the physician. Such loose language is very hurtful to the patient while alive and to the loved ones after death. Our patients and our dedicated medical personnel deserve much better than this.

[3.30 pm]

Hon NICK GOIRAN: It would assist the committee if the witnesses could just indicate if their medical practice has included terminal sedation.

Dr LUGG: That is not true of me.

Dr PATERSON: I work as a psychiatrist. I am going back to my earlier hospital days. Not as a junior doctor, no.

Dr BEAHAN: The answer is no.

The CHAIR: We move to the doctrine of double effect. Would it be helpful, rather than go question by question, if you want to address us on each topic as we move through?

Dr LUGG: What we said about terminal sedation, we are happy to have applied to double effect. It is really the same issue from our point of view.

The CHAIR: Refusal of medical treatment: obviously the refusal of medical treatment can include refusing artificial hydration by patients who are reliant upon others for the necessities of life. In relation to the Rossiter case, is this issue now clear for GPs?

Dr LUGG: I think this is a question that we did not really want to deal with. I think the GP people are much more familiar with that issue.

The CHAIR: Doctors are not under an obligation to administer medical treatment where treatment is futile. A Canadian study found that there was extreme variability of decision-making. Do you believe the outcome would be different if a similar survey were carried out in Western Australia; and, if yes, why?

Dr LUGG: I found this an interesting question because back in November 2016 I actually attended a symposium on futile care and end-of-life matters. It was at the Harry Perkins Institute of Medical Research and it was organised by the WA Audit of Surgical Mortality. It was quite clear that the aim of the organisers was to discourage futile care as much as possible, but it was equally clear that there was a wide range of opinions amongst the something like 250 attendees at this very popular symposium. Based on this experience, I would say there is every reason to believe that a similar survey carried out in WA today would yield comparable results to the Canadian results.

Hon Dr SALLY TALBOT: Who were the organisers of the function?

Dr LUGG: It was the WA Audit of Surgical Mortality. It was a Dr Aitken who was the chair.

Hon Dr SALLY TALBOT: A Western Australian doctor?

Dr LUGG: Yes.

The CHAIR: Can you outline some of the reasons why people were opposed?

Dr LUGG: What I picked up was there was an undercurrent of feeling that what was being preached from the presenters was not always being received by members of the audience.

The CHAIR: In terms of futility of medical treatment?

Dr LUGG: Yes.

The CHAIR: Can you suggest any means by which the value and enjoyment of life by elderly and potentially disabled or chronically ill people and their own preferences may be better able to be factored into considerations of the futility of medical treatment?

Dr LUGG: I had a look at this question. It really goes to the whole question of advance care planning for the elderly, potentially disabled and the critically ill. Advance care planning is a particular interest of our GP section. I really think they will be better placed to talk about that.

The CHAIR: Certainly.

Voluntary-assisted dying: in your submission you indicate that if VAD is introduced into Western Australia, an assessment should not ordinarily require a medical specialist in relation to the disease, nor a psychiatrist in relation to capacity. Why do you say medical specialists should not ordinarily be required?

Dr LUGG: If I could turn that question around and ask why it is that GPs are generally competent and capable to carry out these assessments, I think it is obvious that this is an issue for the GP section. Of course we, as specialists, support our GP colleagues in this regard, but they will talk about why their competence is adequate, I am sure.

There is another aspect of this, though, that goes to the desirability of involving medical specialists, and that is the whole question of waiting times. Waiting times to see specialists, that is the stuff of

newspaper headlines in this country, particularly in Perth. As we know, it can literally take months sometimes for a patient to be seen. We are dealing with a time line here that is completely out of kilter with the needs of the terminally ill if they are going to be dying in a matter of a few days. It does not work very well. The other thing that is worth saying is that to the best of our knowledge, no jurisdiction in the world where VAD laws have been introduced has mandated specialist assessments as a routine. I do not think we would need to get ahead of the pack here at all.

The CHAIR: Does that extend to psychiatrists?

Dr LUGG: That is another question. We do have our resident psychiatrist here, Dr Roger Paterson. I would like to ask him to respond to that question.

Dr PATERSON: Yes, I think that would be very similar, Madam Chair. There is a great shortage of psychiatrists and there would be practical objections or difficulties in responding quickly. That has been recognised by a submission from the local branch of the College of Psychiatrists.

Hon NICK GOIRAN: Have any of the witnesses had an opportunity to read the submission to the committee by the Chief Psychiatrist?

Dr PATERSON: I have.

Hon NICK GOIRAN: You would be aware that he makes it pretty clear that he thinks a comprehensive psychiatric assessment is essential.

Dr PATERSON: I am aware of that, yes.

Hon NICK GOIRAN: Do you disagree?

Dr PATERSON: He is out of step with every jurisdiction internationally and nationally. The Victorian legislation does not propose it. He is out of step with the Royal Australian and New Zealand College of Psychiatrists who say it should be considered, and he is out of step with the local branch who, as I say, recognise that there are practical logistical problems as to why it is not so. Curiously, Dr Gibson suggests it should be mandatory for voluntary-assisted-dying patients to see a psychiatrist, but not mandatory for patients going through the process of terminal sedation. I am not quite sure why he makes the distinction.

Hon NICK GOIRAN: Are there any risks of not requiring a psychiatric capacity assessment?

Dr PATERSON: There is a theoretical risk. Dr Lisa Miller gave a very good account in her submission to the inquiry of a case where on a superficial level one could take the patient's wish for an early death at face value, but on further exploration and expert treatment that wish turned out to be not needed, fortunately. So you may argue that on occasion a psychiatric opinion may be necessary. We would certainly propose that that should happen, but not mandatory; really leave it up to the GPs who are best placed to make that assessment or referral on when necessary. The GPs know the patients over many, many years in many situations. A psychiatrist coming in cold, as it were, would have to start again. GPs are really well placed to make an assessment of cognitive capacity and psychiatric capacity, and if they are suspicious of any impairment they would refer on. I think psychiatrists would be able and willing to get involved at that stage.

Hon NICK GOIRAN: It is an interesting point. In that Miller case you referred to, wasn't the problem that it was not picked up early and it was not until the expert was involved that there was able to be the right treatment provided? So if the GP misses it at first instance and there is not a mandatory requirement to go to a psychiatrist, the opportunity is lost?

Dr PATERSON: Yes. As I say, it is a theoretical problem—in this case a very real practical problem; an actual problem.

Hon NICK GOIRAN: It was an actual problem in the Miller case.

Dr PATERSON: You could be extra, extra, extra careful and insist on a psychiatrist getting involved, but no jurisdiction has that around the world and I can see why; it just would not work. As Dr Lugg was explaining earlier with the pain situation—did you mention that, Richard? The health department were trying to monitor pain prescriptions and suggested a referral to a pain clinic if there is a problem. Very quickly, the pain clinic ground to a halt. It just was not workable. We are not trying to propose legislation that would not work.

[3.40 pm]

Dr LUGG: Yes, I did not mention that, but when I was in the health department one of my jobs was to regulate the prescription of morphine and other opioid drugs which of course have a strong addictive potential. One of the ways in which we did this was to require some patients to be referred to pain specialists.

But the waiting time blew out to the point where it might be six months or more before a patient could see a pain specialist working in pain. You cannot wait that long, so it just became unworkable. While I am talking, Madam Chair, I wonder if I could just mention an anecdote from my earlier years. Some years ago, I was talking with a local psychiatrist—he was local but he was actually born in Hungary—who lived through the Second World War in Hungary. We were talking about suicide. I actually went to talk to him about the suicide of my brother-in-law, which I was very disturbed about. He said to me that suicide could be a perfectly rational option—he was talking about his Hungary during World War II—for people interned and tortured in a Nazi concentration camp where they were going to be killed, they were going to be hurt and they could not get away. He said, “Perfectly rational in a situation like this.” But what he said to me, and it relieved me a lot to hear him say it, was that for a person with freedom of movement and freedom of choice in a country like ours suicide is not a rational option. But what struck me about that is so similar—what he said—to what these patients experience. They are trapped also—not in an internment camp, but in a body—in a diseased-ravaged body that is dragging them down to death. They are going to die and they are suffering unbearably. When you think about it, that is the sort of rational suicide that this psychiatrist was talking about. I think it is the strongest argument for why we should not see a request for suicide in a person under those conditions as some sort of trigger for psychiatric assessment.

Dr PATERSON: Madam Chair, can I make two further psychiatric points. The first is about whether patients with a psychiatric illness alone should be considered as possible candidates for VAD. We would certainly not support that. Dr Gibson made that very clear in his evidence and we would go along with that view. Dr Gibson was also very forceful in underlining the fact that psychiatric patients should not be denied end-of-life choices if they develop a terminal physical illness. Just on the basis of having a psychiatric illness should not exclude them from possible end-of-life treatment. We certainly concur with Dr Gibson’s opinion on that as well.

The CHAIR: Thank you. Your submission indicates that time periods until likely death would be too prescriptive and might exclude some people from accessing a VAD. Can you outline which diseases would result in patients being excluded from a VAD if the time period was clearly prescribed?

Dr LUGG: Yes. In general we are talking about so-called progressive neurological conditions or neuro-degenerative disorders. One of the GP group that you will talk to on Friday actually manages these people. He has firsthand experience of this, and I am sure you will get a good account from him of personal testimony of what it can mean. These conditions are quite rare, but the extended duration of their unbearable suffering is much longer, so the total quantum of suffering these people endure is often greater than those for people who have progressive conditions. Therefore, I do not

think it is right to sweep them under the carpet. A maximum expected duration test is just not the appropriate way to manage these slower, progressive conditions. But what is required is that death should be reasonably predictable. That is important and what I suggested is that it should be predictable on the basis of the following. Firstly, the diagnosis can be properly established, which normally means there is a specialist involved in that. The condition is incurable and the natural course of the disease will lead inevitably to death despite the best medical management that can be provided. In virtually all those cases, there will be either a neurologist or general physician who will have been involved in confirming the diagnosis. Where the expectation is that the prognosis will be greater than 12 months, I think in our view it would not be unreasonable to require a specialist opinion in those circumstances.²

The CHAIR: Your submission outlines Nembutal as the gold standard for assisted dying. Why do you indicate Nembutal?

Dr LUGG: Dr Beahan is expert in these areas.

Dr BEAHAN: The barbiturates in general are very suitable drugs. A lot of experience has been gained about them since their introduction in the early twentieth century. They have been used for epilepsy, for anaesthesia and as sleeping capsules. It was easy to overdose on these drugs and I recall that during the 1960s. They are no longer used as sleeping medication. As an oral medication in an appropriate dose, it will on its own cause depression of the central nervous system with loss of consciousness and cessation of breathing, bringing about painless euthanasia. Secobarbitone and pentobarbitone, otherwise known as Nembutal, have been singled out as the most suitable dying process medications; however, it should be noted that where patients are able to opt for self-administered oral euthanasia or alternatively an intravenous physician-supervised injection, the majority choose an injection. Furthermore, where there are difficulties in swallowing, the intravenous route is preferred. Nembutal has a bitter taste and is given in a volume of 50 to 100 mls, which may be difficult for some to swallow over a short time without gagging. Also, suitable intravenous medications are readily available. Nembutal at the moment is not. It is important that medications used and the mode of administration should be worked out between the patient and the physician, assisted by any protocols established by the professional bodies. The law should not be overly prescriptive in this matter.

The CHAIR: I take it that is why you indicate the legislation should allow for both self-administration and injection by a health professional.

Dr BEAHAN: Yes.

Hon ROBIN CHAPPLE: Thank you very much, gentlemen. Can you give me your opinion on whether a prescription of a type of drug should be included in any legislation or should that be by regulation over time to enable a variety of different medications or suitable medications? Would it be proper to put Nembutal in legislation or should it be left to the GPs and the doctors via a regulatory process in that legislation?

Dr LUGG: We have discussed this, actually. Dr Beahan has pointed out to me how the colleges develop their own protocols to a form of self-regulation, if you like. I think it would be a mistake to actually write a particular drug into legislation. Peter, do you want to elaborate on that?

Dr BEAHAN: I would agree with that. I think we have to come around to regarding assistance with the dying process as being a medical treatment, and medical treatments are not normally put down into law. They are left to the doctor.

² Correspondence from the witness clarifying this part of the transcript can be accessed on the committee webpage.”

The CHAIR: Given some of the concerns raised of the doctor's involvement in, if you like, the intentional killing of their patients could compromise patient–doctor relationship, do you think there is merit in trying to minimise the doctor's direct involvement in the administration of illegal medication?

Dr LUGG: Madam Chair, we understand that these concerns have been raised by the committee and that you are just asking us for our reaction to those concerns that have been raised with you. I think we would like to respectfully point out they are really based on a false premise. As I said in my opening remarks, none of us are in medicine for the purpose of killing our patients. I will not go on in that vein; I have already spoken to that. But what I would like to say is that both parts (a) and (b) of this question raise some really interesting issues but they are really matters primarily for our GP colleagues and I think they will be addressing the details of that question. Madam Chair, while I am talking, could I just ask if we could go back to 13(b)? I think you might have skipped over 13(b).

The CHAIR: Yes, sure.

Dr LUGG: It was one of the matters that we have prepared a slide for you.

The CHAIR: I apologise for that. Which patients, in your view, should have access to VAD?

[3.50 pm]

Dr LUGG: Yes. In general, this question goes to the whole issue of what is required eligibility for accessing VAD. The answer to that question is actually very important because it forms a key part of any VAD legislation, which is why I sort of thought it was worth putting up something like that.³

You will see, first of all, that they have to be over 18; they have to be an adult. Secondly, the legal capability of making decisions is very important. What condition are they are suffering from? You will see I have spelled out there that it has to be a serious, progressive and incurable condition. The patient has to be in an advanced state of irreversible decline. Natural death due to the condition has become reasonably predictable—we can see it coming—and the patient is enduring intolerable physical and/or psychological suffering that cannot be relieved under any condition acceptable to the patient. Then there is the whole request system. You will recognise some of the pattern here from the Victorian legislation. The requests have to be free and voluntary, they must be made without external pressure or coercion, they must be fully informed as to the available treatment options other than VAD and they must be enduring over a time. We suggest at least a week from the first to the last request. Finally, on the question of assessment, it is necessary that there be two independent medical practitioners who independently carry out assessments to assess the fulfilment of the above criteria. I put in a couple of notes there where—I have just run through the criteria, but there are a couple of fine-tuning issues. For example, if both the independent medical practitioners agree that the patient's medical condition has undergone or is likely to undergo unacceptable deterioration before the expiry of a week from the first request, in other words before they would normally become eligible to make a third request, and provide at least one day has elapsed from the time the practitioners have reached that agreement—that is something we have taken from the Victorian legislation—then that third request may be made before the elapse of one week. The second issue there is if legal capacity is lost. If, after the second request but before the third request, legal capacity is lost—this can happen because increased deterioration requires increasing treatment with strong drugs that can be confusing, so it may not be a condition, it may be the treatment of the condition, but for whatever reason, if legal capacity is lost—but before they have entered into this process they had made an advance health directive requesting VAD and this

³ Correspondence from the witness clarifying this part of the transcript can be accessed on the committee webpage."

was in place and what other eligibility requirements were met, then we felt that when the third request is made it should be capable of being lawfully acted on.

The CHAIR: I am conscious that we are reaching the end of our time. Members have a number of questions.

Mr S.A. MILLMAN: Just very quickly, given the importance that you have placed on GPs previously, when you say two independent medical practitioners, independent from whom?

Dr LUGG: Of each other.

Mr S.A. MILLMAN: A treating GP, the family GP, would not be called independent for the purposes of that definition?

Dr LUGG: He could be one of them, but the other GP has to have had nothing to do either with the patient or is not in the same practice for example.

Hon Dr SALLY TALBOT: Why do you set the age at 18?

Dr LUGG: Because we consider it is something that should be reserved for adults. That is just a legal age of adulthood.

Hon Dr SALLY TALBOT: It is the age of majority, rather than any medical or —

Dr LUGG: No, it is not a medical thing.

Hon Dr SALLY TALBOT: — psychiatric concern? There are lots of things you can do when you are 16.

Dr PATERSON: Yes. You are moving into very difficult waters if you start to talk about —

Hon Dr SALLY TALBOT: I do realise that.

Dr PATERSON: —assisted dying under the age of 18 and we must be realistic in proposing realistic legislation. We think 18 and over is acceptable—adults making adult decisions. Under 18 is done in very few jurisdictions throughout the world and we think that is probably a reasonable level to set it at.

Hon NICK GOIRAN: Dr Lugg, with your last slide you quite helpfully provided at the bottom a source of the slide. Are you able to indicate the source of this or is this your own original work?

Dr LUGG: I do not mean to be flippant, but I guess the source is me. But following quite close discussions and, I will not say heated discussions, but thorough discussions, to flesh out where we feel and to establish common ground amongst us. It really reflects the view of the group.

Hon NICK GOIRAN: Does it reflect the view of the three gentlemen before us, or does it reflect the full group of doctors for assisted dying choice?

Dr LUGG: I have circulated this to everyone and I did not get any objections from the people who are not here. I think I can say that it reflects the whole group.

Hon Dr SALLY TALBOT: And it answers a specific question that has been put to you by the Chair.

Hon NICK GOIRAN: Indeed.

Hon COLIN HOLT: Is that reinforced in the tabled paper? That view?

Dr BEAHAN: That view is not specifically addressed in that.

Hon NICK GOIRAN: To finish up on this point—when you say you have circulated it to the group, the submission that we have been provided has been signed by Dr Lancee, then the WA working group members, which have another four names, and then there is a huge chart of names after that. When you say it has been circulated, to whom has it been circulated?

Dr LUGG: I am talking about the WA people. There are six of us. The three here today and the three on Friday.

Hon ROBIN CHAPPLE: I have two questions—one associated with this and then one other one if I may. One of the things that has been a concern in many pieces of legislation around VAD is the issue of VAD tourism. You have not covered it in here. Do you see a need to ensure that this applies only to Western Australians; and, if so, what would you say the time frame around that should be?

Dr LUGG: It is an interesting question because in another body, Dying with Dignity, we have discussed that question. But amongst this group of doctors I do not believe we have. I know what the Dying with Dignity view is, and that is that everyone in Australia is our fellow countryman or countrywoman and we should not be withholding help from them. But since we have not discussed it ourselves, I do not think we have a specific view.

Hon ROBIN CHAPPLE: I want to go to something completely different, if I may. When it comes to DNR, do not resuscitate, who makes that decision and on what basis?

Dr LUGG: I think that that really is something that is derived from an advance health directive. If the advance health directive spells out that the person is not to be resuscitated under the circumstances and so on, someone has to put a sort of a shorthand version of that above the bed so that staff who have not had the benefit of looking at that who are rushed in when the person collapses or something, have no idea and have never seen the patient—"Oh, DNR." It just tells them there is an advance health directive here. It gives them the clue that they should not resuscitate.

Hon ROBIN CHAPPLE: Was DNR not used before advance health directives?

Dr LUGG: I am sure it was and I am sure it is also used where advance health directives have not been completed. But the proper legal status would derive from an advance health directive.

Dr PATERSON: I think it is a very good question, because it is unclear sometimes where the DNR has come from. It is again a rather murky sort of legal area.

Hon ROBIN CHAPPLE: We do not expect somebody to crawl to the bottom of their bed and write on it.

Dr PATERSON: Exactly. It is an area of confusion.

The CHAIR: 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 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 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. The committee will write to you with any questions taken on notice during the hearing and we will include the proposed questions that we unable to address due to time constraints.

Hearing concluded at 3.58 pm
