

# **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 TWO**

### **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**

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**Hearing commenced at 10.28 am**

**Prof. LINDY WILLMOTT**

**Legal Academic, Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology, examined:**

**Prof. BEN WHITE**

**Legal Academic, Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology, 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-Jane Sanderson and I am the Chair of the Joint Select Committee on End of Life Choices. I would like to introduce the other members of the committee. We have Simon Millman, 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 you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege in Western Australia and protected by uniform defamation laws in Australia against actions and defamation; however, this privilege does not apply to anything you may 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.

Could you please introduce yourselves for the record?

**Prof. WILLMOTT:** Lindy Willmott.

**Prof. WHITE:** I am Ben White.

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

**Prof. WILLMOTT:** No, thank you.

**The CHAIR:** Before we begin with our questions, would you like to make a brief opening statement?

**Prof. WILLMOTT:** Yes, if I could, thank you.

**The CHAIR:** Please do.

**Prof. WILLMOTT:** We would like to say thank you for the invitation to give evidence before the committee today. As I said, my name is Lindy Willmott. I am one of the directors of the Australian Centre for Health Law Research, which is part of the Faculty of Law at the Queensland University of Technology. My colleague Professor Ben White is the other director of the centre. Just by way of background, the centre comprises more than 20 full-time academics, most of whom are lawyers, and we research in a wide range of health law topics. I should say at the outset that the views that we express today are our own, based on our own research in the area, and do not purport to represent the views of others in the centre, the law faculty or at QUT.

For the sake of transparency, before the committee asks us specific questions, we would like to state our position in relation to assisted dying, as many of the committee's questions to us are on the issue. We believe that the current laws should be reformed to allow assisted dying in limited circumstances. We believe that a law of this kind would promote values that are important to a

liberal democracy—values of life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, and reducing human suffering. We believe that an appropriately drafted law that permits assisted dying would protect the vulnerable in our community. We are happy to discuss our thoughts on what such a model would look like if that would be helpful to the committee, but we note that we have outlined our preferred model in chapter 26 of the text *Tensions and Traumas in Health Law*, which has been forwarded to the committee already.

There is one final point that we would like to make here. The committee has been provided with many submissions and will hear much evidence. We are conscious of the broad and diverse expertise of the committee members, but we wanted to take an opportunity to repeat a point that we made in the material attached to our submission about weighing this evidence. With our colleague Dr Andrew McGee, we wrote a piece for *The Conversation* about this point. I think it is on page 86 of the first volume of the document submitted as an attachment in which we invited Victorian politicians who are considering their bill to distinguish between claims about morals—for example, all killing is wrong—and facts which depend on evidence. In relation to weighing that evidence, we drew on a reliability pyramid and included a diagram proposed by our colleague Professor Jocelyn Downie. We invite you to question what evidence people are putting forward to back their claims about assisted dying laws. At one end of the spectrum is anecdotal evidence— anecdotal claims of what people claim to have seen or done, which is of limited reliability. At the other end of the spectrum is a systematic review which puts together all the research done on a topic and critically evaluates it. Ideally, that research is then further externally reviewed by another body such as a court or, in this case, a parliamentary committee. This point is particularly important in the context of a claim often made that it is impossible for any legislative regime to be drafted in a way that protects vulnerable people. Assisted dying has been lawful in some international jurisdictions for a long time. There is much research into how the regimes are operating in practice. This research has been published in prestigious peer-reviewed journals and provides evidence that the vulnerable are not at risk as a result of legalising assisted dying. Again, we are happy to talk to this point further during the session. Thank you. That concludes our opening remarks.

**The CHAIR:** Thank you. You have been sent through the questions, I understand, so we will go straight into the questions. In relation to the Australian study “Opioid errors in inpatient palliative care services”, could you comment on whether likening opioids to any class of drugs underestimates the levels of risks associated with its use?

**Prof. WILLMOTT:** I acknowledge that comparisons were made between opioids and other classes of drugs in the article that you refer to. In answering your question, though, it might be useful to provide some context to the comment. The article that we published in the *Internal Medicine Journal* was predominantly a legal analysis which compared the common law doctrine of double effect with the statutory protections that had been introduced in three Australian states and one territory. The common law doctrine arose because there was a concern that a doctor could be held liable if a patient died following the provision of pain or symptom relief. The legal common law response is that a doctor will not be liable for the death even if death is accelerated by the medication if the intention of the doctor was to relieve pain and not accelerate death. In some jurisdictions, as I mentioned, the defence is incorporated in a statute. Our legal analysis indicated that there may be less protection under statute than under the common law because to get the statutory protection, you must demonstrate that the administration of the medication meets certain standards of care. Ben and I co-authored that article with a pal-care physician whose view is that the appropriate titration medication will not result in death. In the paragraph of the article that this phrase comes from we state that there is no evidence that appropriately administered medication will result in death, but we went on to concede that opiates, like other drugs, are

dangerous if applied inappropriately. In the context of the article, I think we are suggesting that there could be serious consequences for patients if administered inappropriately. We do take the point that serious consequences can flow if an inappropriate dose is given.

**The CHAIR:** One view raised in evidence before this committee is that the doctrine of double effect is no longer required. Would you comment on whether or not you agree and why?

**Prof. WHITE:** Sure. I will answer this one. Based on the information that was provided with this question, we understood that the evidence being referred to is, basically, that palliative care properly administered in fact need not hasten death, as Lindy mentioned before. The argument then is that if this is the case, legal protection is not needed. We will talk about this, I guess, in response to the next question—whether or not that is clinically the case is probably something that is beyond our expertise. That is a clinical issue. We would say—and I expect you have heard this evidence before—in conversations with some medical colleagues, they say that it need not hasten death, but there are other medical colleagues who have reached the view that in some instances where a patient is close to death there is a prospect of that happening. There are, I guess, different views clinically on it. A relevant consideration from our perspective, putting aside whether or not it does in fact hasten death, is whether a perception that it does can exist. There is a body of anecdotal evidence in the public domain about this, including, for example, the Australian Commission on Safety and Quality in Health Care's work in the end-of-life area, the Victorian end-of-life choices inquiry and, indeed, I imagine you have heard evidence in this forum as well. We also have some pilot research, which is not yet published, which reveals concerns that [inaudible] —

**The CHAIR:** Professor, can you repeat that last sentence? I missed that.

**Prof. WHITE:** Sure. We have some pilot research, which we have been doing as part of some funded research about the role of healthcare professionals' perspectives on palliative care. It is not yet published—it is only a pilot—but there were some concerns revealed in that research about law or fear of law impeding best practice in terms of palliative care. Our view as to what an appropriate legal response might be in light of that is twofold. Firstly, the law or fear of law—and whether that is a misplaced fear or not—should not get in the way of appropriate, high-quality palliative care. Double effect may in fact serve two useful functions, which I will set out. First, if palliative care may hasten death, and we noted before that is a clinical question, then it has a function to play. Secondly, double effect may also serve a useful function in that it provides a clear statement to ensure that fear of law or misplaced perceptions about what law may say does not result in underpalliation. Where there are possible grave consequences—we are talking about potential criminal responsibility for the death—the law should be very clear that it protects appropriate, high-quality palliative care.

[10.40 am]

**The CHAIR:** You expressed a view that opioids do not suppress respiratory function and hasten death if administered properly. Given the trajectories of different terminal illnesses vary markedly, do you think there is sufficient evidence for this conclusion to be applied across palliative care?

**Prof. WHITE:** That statement that you mentioned, as Lindy touched upon, appears in a paper where we collaborated with a palliative care physician, and that was based on his clinical expertise and his clinical knowledge on that point. That probably falls outside our field of expertise and we consider it is probably best addressed with others.

**The CHAIR:** Do you think that concern about double effect of pain relief might be contributing to the underdosing of opioids as identified in an Australian study?

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**Prof. WILLMOTT:** We think that is certainly possible, and I guess there are a couple of parts to your question. The first is whether health professionals might be concerned that providing medication may also result in a death, and the second part is whether that results in under-palliation or not providing sufficient pain relief to alleviate pain and suffering. Both of these questions are important and there is not much evidence in relation to either of them, as far as I am aware. A related question that we are exploring, as Ben mentioned, is whether the concern about potential legal or professional consequences of the patient dying after receiving medication leads to under-palliation. We think more research is required into that, but we do note there is certainly some anecdotal evidence at the moment. It has been recognised in Australia recently that this might be the case. That is in terms of the Australian Commission on Safety and Quality in Health Care in 2012 or 2013 observed that fears held by clinicians about complaints or possible vilification can result in avoiding dealing with dying patients.

More recently, the Legislative Council Legal and Social Issues Committee of the Victorian Parliament in 2015 and 2016 noted the evidence by a pall care specialist there that it is not uncommon to have a scenario on the ward where the nursing staff are fearful that if they give the injection and a patient dies, there will be repercussions for them. But this is just isolated anecdotal evidence and we think more research is required. As I said, we are seeking to explore that empirically. I might say, as a related issue, we have recently done a review of all Australian cases where there has been an allegation that there has been overmedication and that has resulted in death. Our review has indicated very few cases where health professionals have been held to account as a result of providing medication that has resulted in the death of a patient. We have written up all these results and they are currently in a journal article and we have submitted it for publication. We are just going through the peer assessment process at the moment.

**The CHAIR:** Given that consent is not an express requirement under the terms of section 259(1), why do you think it might be read in as a requirement?

**Prof. WHITE:** Thank you for the opportunity to clarify our submission on this point. We do suggest that consent may be needed to rely on section 259 as part of that treatment being reasonable, but we should perhaps qualify our perhaps abrupt statement in our submission with the longer version of what we have written in our paper in the *Internal Medicine Journal* and also in the textbook *Health Law in Australia*. I think both of those texts are in the documents that we provided as part of our submission.

Our position is that section 259 can only be relied upon when the provision of treatment is reasonable. That is, basically, from the terms of the statute itself. We think a relevant consideration in assessing whether or not treatment is reasonable would depend on whether consent had been obtained or not. So, putting aside emergency or settings where it is not feasible to obtain consent from a person or substitute decision-maker, providing treatment, obviously, without consent is unlawful without other justification. So treatment has to be reasonable in the circumstances to fall within that provision. It may be hard to argue that unlawful treatment, again assuming consent could not have been obtained, falls within that notion. Of course, this would be determined by a criminal law process and it is not a specific requirement of consent, as there is, for example, in the South Australian legislation. But we believe whether or not consent was obtained would go directly to that question of whether treatment was reasonable as required by section 259, particularly given that this treatment may potentially hasten death. Treatment without consent that may hasten death, that would touch very directly on whether the treatment would be regarded reasonable.

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**Hon NICK GOIRAN:** Thanks, professors, for meeting with us today. I have a question in respect to that last point on section 259(1). Unfortunately, I do not have a copy of that section in front of me at the moment; looking around, I do not see any of my other colleagues who have it available either. But if I understood what you were saying, I think you are indicating to the committee that consent is implied in interpreting 259(1).

**Prof. WHITE:** Thank you for that question. It is good to clarify that. I do not know if we would go so far as to say it is implied in terms of being a definitive requirement. But I would go so far as to say that we believe when assessing whether or not treatment is reasonable, that is sort of the crux of whether or not the excuse would apply—the defence would apply. Providing treatment which is unlawful in a serious setting would have implications for whether or not a fair criminal process would regard that treatment as reasonable. I am not trying to be indirect, but I think we probably would not go so far as to say it is implied as a requirement, but it is very likely to be an integral part of whether treatment is reasonable or not.

**Hon NICK GOIRAN:** Would you describe it as a factor that would be considered when interpreting what is meant by “reasonable care and skill”?

**Prof. WHITE:** I think that is a good way to describe it. It is a factor, and arguably an important factor given that its absence would make the treatment otherwise unlawful.

**Hon NICK GOIRAN:** Are you aware of any cases where this issue has been tested?

**Prof. WHITE:** That specific point about whether consent is required or not, I am not. Section 259 was considered in the *Brightwater v Rossiter* case, but that specific point about the likelihood of consent being required or not, I am unaware of a case. Lindy?

**Prof. WILLMOTT:** No, I am not aware. I do not think it was considered in *Brightwater’s* case, whether consent —

**The CHAIR:** We will move to palliated starvation and dehydration. The South Australian Supreme Court considered that a competent person’s refusal to eat or drink did not constitute suicide. Can you comment on the applicability of that reasoning in a code jurisdiction such as Western Australia?

**Prof. WILLMOTT:** Certainly I can, and I am familiar with the case and the comments made by the judge in that case. I would not regard myself as a criminal lawyer or criminal law expert, but we have considered about the voluntary stopping of eating and drinking and whether that constitutes suicide in an article with Julian Savulescu, published in the *Journal of Law and Medicine*. This is a really important but difficult point, I think, and there is little discussion about precisely what constitutes suicide in the primary material such as cases and legislation in Australia. This is probably because traditionally we all understand what that term incorporates—the intentional taking of one’s life, for example, gunshot wound, hanging, jumping in front of a bus et cetera. That is universally accepted as constituting suicide.

We are now hearing of cases where people with life-limiting illnesses sometimes are choosing to stop eating and drinking to accelerate their death, but there is a divergence of opinion about whether or not that legally constitutes suicide because there just has not been much on it in the statutory or the primary material. We note the comments of Justice Kourakis in *H Ltd v J*. That South Australian case concluded that stopping eating and drinking is unlikely to constitute suicide and is on a join analogy with refusing medical treatment, which is not regarded as suicide.

But I should flag that there is a difference of view in the literature about whether or not stopping eating and drinking should be regarded as suicide. There is a recent article that the committee might want to have a look at by a colleague of ours, Dr Andrew McGee. He recently published an article in *BMC Medicine*, and he argues that it does constitute suicide. So maybe there is still some distance

to travel in this debate before there is a concluded position on that. But back to the question that you put—that the reasoning in South Australia would apply to WA, which is a code jurisdiction—in my view it is likely that the same reasoning about what is and what is not suicide would carry across to a code state. The matter is less about the difference between code and non-code jurisdictions, I think, and more about the conceptual nature of what is suicide.

[10.50 am]

**Hon NICK GOIRAN:** Professor, if I heard you correctly, you refer to a recently published article by a colleague of yours and you have encouraged the committee to have a look at that. I think I am hearing you say that that colleague has taken a different view to the judge in the South Australian Supreme Court case—is that right?

**Prof. WILLMOTT:** Yes, that is right. That is correct.

**Hon NICK GOIRAN:** Do you think it would be reasonable for the committee to give greater weight to the view of the judge in the Supreme Court case rather than one of your colleagues in an article?

**Prof. WILLMOTT:** Absolutely. The Supreme Court is an authority that is binding in South Australia. My colleague is a philosopher and a lawyer, and he has referred to that judgement, unpacked the reasoning behind the conclusion that it is suicide, and draws philosophical distinctions between stopping eating and drinking, and concludes in his view that it is the intentional taking of life and therefore does fit that definition of suicide. But I guess my point is that there is not much primary material on this yet. The voluntary stopping of eating and drinking is a relatively novel practice and it has not been considered much by the courts or by Parliament. That is what one South Australian judge said; maybe another judge might take a different perspective. But I take your point—certainly in legal terms, that has more weight than what my colleague suggests.

**Hon NICK GOIRAN:** Thanks, Professor. Unfortunately the committee has not been provided with a copy of this South Australian Supreme Court case. Would you and your colleague be available for further questions in the future should we want to pose them on this topic?

**Prof. WILLMOTT:** Of course; delighted to.

**Hon NICK GOIRAN:** Thanks.

**The CHAIR:** Your submission recommends that the WA Criminal Code be amended to allow for the practice of palliative starvation and to protect doctors providing palliative care in these circumstances. Given that suicide is not an offence under the Criminal Code, can you expand on the reasons why it would be useful to specifically allow for the practice of palliative starvation under the code?

**Prof. WHITE:** Yes, of course. The issue that we were thinking about here is not so much the liability of the patient themselves—we take the point that suicide would not be a criminal offence—but rather the clinicians who may be called upon to assist them through the provision of palliative care. So it is not about suicide but rather removing doubts that providing palliative care to someone who is dying in this way is not unlawful and would not constitute assisting suicide. Our view as a matter of policy is that if a competent adult has chosen to stop eating and drinking with a view to ending their life, and they would like palliative care to manage their pain and symptom relief as it occurs as they are dying, it should be lawful to provide that care. In the article in the *Journal of Law and Medicine* which I mentioned earlier, there is case authority which makes it clear that it is lawful to provide palliative care to someone who is refusing artificial nutrition and hydration and is dying as a result of that, and we think it is appropriate that this case be treated in the same way. But at the moment, without clear guidance from the law, there is an uncertainty. I return to the starting point where we spoke about the relationship between law and palliative care, and that is that uncertainty

about law should not impede appropriate high-quality palliative care, and that where that uncertainty exists, it is appropriate to address it. In our submission, I am not sure we suggested that there needed to be changes necessarily to the Criminal Code. I think we made the broader point that whether it is through the Criminal Code or other regulatory changes, I will defer to others, but our policy position is that there is currently uncertainty as to what is lawful, and we believe that uncertainty should not exist.

**The CHAIR:** Thank you. Other than who is ultimately making the decision, can you elaborate on any other differences between the two practices of terminal sedation and palliative starvation?

**Prof. WILLMOTT:** Certainly. I obviously do not have clinical expertise, but I can provide my understanding of these terms based on my reading of the research. As I understand the terms, they are different practices and they are used in entirely different circumstances. In terms of terminal sedation, my understanding is that this practice is relatively infrequent in clinical practice. It is used when a patient is approaching the end of life and has refractory symptoms—symptoms that just cannot be managed by the usual pain and symptom relief—so the person is sedated to the extent that he or she becomes unconscious, and he or she will remain that way until death. This practice has received relatively little legal or ethical analysis in Australia to date. For example, there may be questions around the illegality of the practice when it is coupled with stopping the provision of artificial nutrition and hydration at the same time that sedation is administered. Terminal sedation is arguably lawful because it is intended to address a person's pain and suffering. But the legality of stopping artificial nutrition and hydration might be more questionable because that is harder to link with other pain and suffering. So I guess the point is that there is still some legal and ethical uncertainty around that practice. Palliative starvation, there are two components to this. The first is a decision by a competent person to stop eating or drinking. This is likely to occur when the person is at the end of life or approaching the end of life and they have made the decision they would rather die sooner rather than later as a result of the natural progression of disease. The second component is the provision of palliation by a doctor, and medication will be provided if a patient incurs pain or suffering, and this can be as a result of the original illness or it can be a direct result of the stopping eating and drinking. To reiterate, they are entirely different practices and they occur in different circumstances, and they involve quite separate legal and ethical issues.

**Hon NICK GOIRAN:** Further to that last point, is consent required in both practices?

**Prof. WILLMOTT:** That is a really good question. In terms of terminal sedation, good medical practice, I would have thought, requires consent to be given either by the patient, or, if the patient is so unwell that they have lost the ability to consent, it would have to be obtained by a substitute decision-maker. In terms of palliative starvation, the first component, a person can decide to stop eating and drinking, but again the palliation given to that person, because it is a medical treatment, I imagine there would have to be consent, and if they have become unconscious, I imagine consent to palliation would have to be given by a substitute decision-maker.

**Hon NICK GOIRAN:** Thank you.

**The CHAIR:** Are you able to advise of any relevant studies on terminal sedation in Australia?

**Prof. WILLMOTT:** No; we are not familiar with any studies on terminal sedation in Australia. We believe it is an under-examined area.

**The CHAIR:** Do you think it is legitimate to assume that there would be significant commonalities between Australia and the UK in relation to the approach to palliative care?

**Prof. WILLMOTT:** Again, this is probably one that falls outside our expertise, and I think other people would be better placed to comment on that question.

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**The CHAIR:** Okay. Along the same lines, and you may answer in the same way, do you think it is reasonable to extrapolate that similarly high rates of terminal sedation are likely to be found in Australia as they are in the UK?

**Prof. WILLMOTT:** Yes; again, that is probably outside our area of expertise.

**The CHAIR:** Thank you.

**Hon NICK GOIRAN:** Professors, in the questions that you were provided just then on end-of-life terminal sedation, there were some notes made in the footnotes and there is different terminology used between terminal sedation and continuous deep sedation. Are you in a position to inform the committee of the differences between the two?

[11.00 am]

**Prof. WILLMOTT:** Yes, absolutely. There are a whole lot of different terminologies. There is palliative sedation. There are all sorts of different terminologies. You are right. This is beyond my expertise. In Europe, the palliative care group, the peak group, have a paper which talks about guidelines for terminal sedation and they refer to a whole range of different terms that are used for that particular practice and they do highlight some differences. That was the European Association for Palliative Care. It is in footnote 5 on page 4 of our submission.

**Hon NICK GOIRAN:** Is continuous deep sedation a form of terminal sedation or is it one and the same thing?

**Prof. WHITE:** I think one of the challenges here is that depending on who you are talking to, that question may be answered in different ways. Although it has been happening for some time, thinking in a structured policy way about what each of these incremental steps might look like, it is starting to evolve, but there is probably a lack of policy guidance or lack of shared terminology, which means that the question you have just asked is a really, really good one, because different people may answer in different ways. I am not sure the position is sort of adequately defined, other than to point to the most authoritative guidance that is currently available, which is the European guidance, other than to note that people are using those terms in different ways. Sometimes they mean the same thing; sometimes they mean different things.

**The CHAIR:** We will move to the next set of questions. Could you please elaborate on your views on the validity of slippery slope arguments and on the risks to the vulnerable in reference to assisted dying and euthanasia?

**Prof. WHITE:** We understand this question to be about whether assisted-dying regimes pose risks to vulnerable groups in society—for example, whether vulnerable groups will be disproportionately represented in their access to the regime. Generally, this argument is framed in terms of being likely to occur because safeguards do not or will not work adequately. In answering this question, we might return to the reliability of evidence pyramid that we mentioned at the outset. We have looked at a range of evidence in this and we are aware of anecdotal evidence and assertions that are sometimes made in relation to this. We give very limited weight to anecdotal evidence. By contrast, we place great weight on reliable peer-reviewed evidence published in some of the best journals in the world and the information I will just mention briefly shortly. We note that the Canadian courts had cause, as part of their deliberations in the Carter case, to evaluate this peer-reviewed evidence and they reached the same view. What that body of peer-reviewed evidence says is that it is possible to design an assisted-dying regime that properly protects the vulnerable. Some of this evidence is extracted in our book chapter, which we have provided to the committee, “Assisted dying in Australia: A values-based model for reform” in that text *Tensions & Traumas in Health Law*.

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Just very briefly, one of those papers that we refer to is a systematic review of evidence from assisted-dying regimes and how they operate over an 11-year period published in the very well respected journal *Social Science & Medicine*. The authors there concluded that assisted dying is less often practised for the elderly, women and less-educated patients. Another paper we refer to is published in *The Journal of the American Medical Association*—JAMA—another top journal by a group of authors. We understand within that author group, there are people who are in favour of assisted dying and those who oppose assisted dying, so the paper obviously has had a consideration of this evidence which looked at both sides of the argument. It concluded that typical patients accessing assisted dying are older, white and well educated. There are other papers as well. The one I might also mention is the paper which examines the first 18 years of the operation of the Oregon assisted-dying regime. For example, it found that 71 per cent of people who received assistance had some form of tertiary education—so, a very well educated group.

I should say, in answering this question, protecting the vulnerable is actually very, very important to us. It is a value that we specifically identified in that book chapter I mentioned as being very important for the dying and assisted-dying regime. We have done a body of research in related fields about ensuring that vulnerable groups are not discriminated against in accessing life-sustaining treatment. This is a topic we take very seriously, but we follow the evidence and that shows that claims about the vulnerable being at risk from these regimes—those slippery slopes that were mentioned—are not substantiated.

**Mr J.E. McGRATH:** We were told in some of this anecdotal evidence that has been referred to us as a committee and we were given some examples from places such as the Netherlands, where a fairly young person who is suffering from depression has decided that they want to end their life and then they go to a practitioner and the family finds out a bit later on that that person has gone—is no longer alive—and there have been some court cases. I think in the court case in one situation the family failed in the court, so the practitioner's actions were upheld. Are you saying this is an area that you would agree to if we agreed to this in Western Australia? Is this something that you think could be accepted—where a person is in a state of depression or has a mental illness, but they are not about to die?

**Prof. WHITE:** Our view on that, and again we have that book chapter which outlines our values-based approach to constructing an assisted-dying model, is that would fall outside what we think the law should say in that instance, because it required as part of that values-based model that someone has—I can find the words in the text if you would like, but the essence of it is—a serious and incurable medical condition that will cause death.

**Mr J.E. McGRATH:** So are you refuting that this has happened in jurisdictions such as the Netherlands? Is it fact or is it just anecdotal evidence that might not have happened?

**Prof. WHITE:** Sorry; I may have misunderstood your question. I thought you were asking me whether I thought that in the example you gave it was appropriate to be part of an assisted-dying regime. So that was the question I was answering. The question that you are asking is did this happen. Is that basically what you are saying?

**Mr J.E. McGRATH:** I asked whether you believe it has happened. Is that, in fact, a fact and not just anecdotal; and, if it is true that it has happened, is that something that you would accept in our jurisdiction in Western Australia?

**Prof. WHITE:** Whether or not it is a fact, I think, would depend on what evidence there is to support that. For example, if you were talking there about there being a formal court hearing and publicly available information, that would inform my view about whether or not I was prepared to accept that that had happened. One of the challenges—I have written a paper on this looking at some of

the discussion that we have seen in the media about what is happening in the Belgium regime, for example—is some of that discussion we are seeing in the media is based on incomplete information. It is based on one side of one person's story or those sorts of things. So one of the points made in that paper, is that if we are going to look at specific case studies—specific instances like the example that you have given there—it is worth carefully interrogating what the sources are, how reliable they are and whether or not we think that what is being said to occur in, for example, the media or otherwise actually has occurred. I guess that is the comment I would make. I would be interested to know what the evidence is, how reliable it is and sources.

**Prof. WILLMOTT:** Can I just add, if I may, that in relation to the Netherlands regime, it is an entirely different legal regime, so what might be lawful in the Netherlands is not lawful, for example, under the new Victorian regime. Under the Victorian regime, you need to be an adult and you need to have a terminal illness. So even if that evidence put to you in relation to the Netherlands regime is correct, whether or not that should be permitted in WA is a matter for the parliamentarians as to the scope of the regimes. Certainly in Victoria they have a very conservative model. As I said, only people who are adults, who have the capacity and who have a terminal illness and are likely to die within six or 12 months would be able to access assisted dying.

[11.10 am]

**Hon NICK GOIRAN:** Professors, the question the Chair asked a moment ago had a footnote, and I understand you have that available. My notes state that in your submission you indicate that research conducted in 2012, which has data on assisted dying in the Netherlands, Belgium, Switzerland and Oregon, is not broadly indicative of a slippery slope. The information that has been provided to the committee is, of course, a summary. I want to clarify: do you stand by that summary, that your research conducted in 2012 of those jurisdictions is not broadly indicative of a slippery slope?

**Prof. WHITE:** Could you clarify what footnote number that is?

**Hon NICK GOIRAN:** Footnote 14.

**Prof. WHITE:** I might just read it, if that is okay. I guess the point we would make there is that that is research we have referred to; it is not our research. If I recall, or recognise the wording properly, that would be our submission referring to other research. I would expect—I do not have the references that are there so I am not entirely sure which exact paper that is being referred to—it would be peer-reviewed evidence that met the criteria that I spoke about before.

**Hon NICK GOIRAN:** Can you clarify for the committee whether either of you have researched the Netherlands' law?

**Prof. WHITE:** We have written about the law, but we have not conducted empirical research in the Netherlands about how the Dutch regime operates. But we have included in some of the writing that we have done a description of what the Netherlands law is and what it states.

**Hon NICK GOIRAN:** I did have a range of questions for you in respect of this issue, but I know that you both quite rightly make the point that we need to be dealing with empirical evidence. If you have not researched the Netherlands' law specifically, then perhaps it is not productive for me to ask you questions about whether there has been a slippery slope in the Netherlands.

**Prof. WHITE:** Maybe a way forward is if there are specific papers that you were interested in, we would certainly be happy to comment on our view on what that particular paper says about the operation of the law in the Netherlands. We would certainly be happy to do that at a future time, but I take your point that detailed engagement with particular pieces of research might be better conducted in that way.

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**Mr S.A. MILLMAN:** Further to Hon Nick Goiran's question on the law in the Netherlands—perhaps this might assist my understanding of what you are saying—when you say that you have not examined the empirical evidence, presumably you have looked at the provisions in the statute in the Netherlands. If that is right, can I ask whether or not, from when they were first enacted until your most recent examination, they have changed in order to expand the category of people who are able to access voluntary assisted dying or voluntary euthanasia? That is a question of law, I suspect. Is that a different analysis to a question of fact—that is, how have these laws been applied in practice—which is, from what I understand it, a study you have not done?

**Prof. WILLMOTT:** Our understanding is that the Dutch law has not altered since it was first enacted. When it was first enacted, minors, in some circumstances, were entitled to access assistance to die, but that has not been altered in the Netherlands. Also in the Netherlands, in certain circumstances, if they put their requests in a formal document and then they later lose capacity, then they can also seek assistance to die. I understand that there is currently some review in the Netherlands about whether or not they should be reforming the Dutch law around euthanasia, but, as yet, it has not been changed.

**Hon COLIN HOLT:** To follow up on that, what about other jurisdictions besides the Netherlands?

**Prof. WHITE:** I might answer and give two examples: one is Oregon, which is, apart from the Northern Territory, the first operative assisted dying regime in the world. It is the longest standing in operation and it is the one most like the Victorian model. It has not changed in terms of its scope. One jurisdiction has extended its law, and that is in Belgium; although, I think in 2013 or 2014, there was a small expansion of the law in Belgium to enable what we would call Gillick competent minors—so children say older than 17 who have a full understanding of the nature and effect of the decision they are making—to have access to assisted dying. It is my understanding—I should say that I last looked at this about six months ago; that law, I think, was passed in 2014—that had been accessed, when I looked at this about six months ago, by one 17-and-a-half-year-old patient who had terminal cancer and was in unremitting pain. One of the things that I think the discussion about whether laws expanded or not, the change to the Belgium law is very, very narrow and, as I understand it, has been used once, at least when I looked at it six months ago.

**Hon Dr SALLY TALBOT:** I want to encourage Hon Nick Goiran to go ahead and ask his questions about other jurisdictions, because if I have understood you correctly, you have followed a standard process in doing academic research, of doing a review of research that looked at a specific question about the protection of vulnerable people and formed your own conclusions that none of that research validates concerns about slippery slopes. Am I right in hearing you that way?

**Prof. WHITE:** Yes, that is correct. As part of that process of reaching our own view on how the law is operating in the Netherlands, we have reviewed the various peer-reviewed evidence that is available about how the Netherlands regime is working in practice, and that is what our view is based upon. So, yes, I can confirm that. I guess my point was that if we were to be asked about specific papers, it would be helpful to have them prior to be able to read them and to provide detailed feedback about that. But, looking at the evidence as a whole, I think the points I made before about the peer review evidence not showing that slippery slopes have eventuated is accurate.

**Prof. WILLMOTT:** Could I add that the Supreme Court of Canada in the Carter decision took evidence about the slippery slope as well. It looked at all the available peer-reviewed evidence itself and concluded that there was no evidence that people who were vulnerable were at risk under the assisted dying legislation.

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**Hon Dr SALLY TALBOT:** It will be up to my colleague to decide whether he proceeds with that line of questioning, but are you confident that we have all the references that we would need to follow up those questions, or is there further material that you could provide to us?

**Prof. WHITE:** The book chapter I mentioned has what are often described as the seminal pieces on it, and we also include some very recent pieces, but there is other literature that we could provide to the committee that would provide a wider body of peer-reviewed evidence to consider.

**The CHAIR:** We will follow up with you and get some of those references.

**Prof. WHITE:** Thank you.

**The CHAIR:** Professor Lindy Willmot, did you want to add something there?

**Prof. WILLMOTT:** I was just going to say that it might be valuable to have a look at the Supreme Court of Canada decision in the Carter case because they referred to that literature and they also had a lot of expert evidence before them to talk to that literature as well. There was examination and cross-examination in which these issues were explored.

[11.20 am]

**The CHAIR:** In your submission, you indicate that you prefer a permissive rather than a defence model for legislating-assisted dying. Can you explain those terms and elaborate a bit further on your view of the benefits of the permissive model?

**Prof. WILLMOTT:** Yes, certainly. We use those terms in the article “(Failed) voluntary euthanasia law reform in Australia”, which was published in the *University of New South Wales Law Journal*. We analysed all of the attempts to reform the law that had occurred in Australia—I think it was up until the end of 2015. There were more than 50 models, so we looked at all of those models and we analysed them and categorised them. One kind of category was the permissive model versus defence model. Most of them fell within the permissive model. What we mean by that is models that provide a legislative framework which integrates safeguards, thereby positively allowing euthanasia or assisted dying. So it is sort of a set of provisions, generally in an independent piece of legislation, which sets up a whole legislative framework. We call it permissive because under such a model, if a medical practitioner complies with the requirements imposed under the framework, no offence is committed, so the onus is on the prosecution to prove that the practitioner failed to comply with the provisions. The recent Victorian legislation is an example of a permissive model.

On the other hand, the defence model provides criteria which, if satisfied, will constitute an effective defence to a charge of murder or manslaughter, for example. Under this model, euthanasia or assisted dying would remain a criminal offence, to which the defendant would have a defence if he or she could show that they complied with the requirements of the defence provisions. This is an uncommon sort of model, and of more than 50 bills that have been put forward over the last couple of decades, there were only two that fell within this category. We prefer the former—the permissive model—for a few reasons, I guess primarily for the reasons that we articulate more fully in chapter 26 in the textbook, *Tensions and Traumas in Health Law*. We believe that assisted dying should be permitted in some circumstances. We believe that the practice will promote important values, including the value of life, autonomy, equality, rule of law and so on. A permissive model would reflect parliamentary endorsement of that position, so assisted dying would be allowed in some circumstances if Parliament thought that was the appropriate thing to do. Secondly, framing the practice as lawful may assist health professionals who assist people to die within the criteria prescribed by the legislation, whereas under the defence model, the conduct remains unlawful, but would be excused in certain circumstances. So the stigma of the criminal law is still attached under

the defence model. I guess, related to that, the third reason is that under the permissive model, the activity is lawful on its face and the onus would be on the prosecution to prove otherwise.

**Hon NICK GOIRAN:** Further to this, professors, did your assessment of the permissive and defence models include any jurisdictions where those models are in place, or was the assessment limited to jurisdictions where the models were proposed?

**Prof. WILLMOTT:** The analysis that we undertook and referred to in that paper is of Australia. So in all Australian jurisdictions over the last 20 to 30 years, we reviewed more than 50 of those models—all of the bills that were proposed. But I do note in most of the jurisdictions internationally where it is lawful, they are permissive rather than defence models.

**Hon NICK GOIRAN:** Have you had an opportunity to assess those permissive models in the other jurisdictions?

**Prof. WILLMOTT:** As part of our research in the area, we have looked at the permissive models, yes.

**Hon NICK GOIRAN:** In your assessment of those permissive models in the other jurisdictions, have you had an opportunity to assess the error rate?

**Prof. WILLMOTT:** What do you mean by the error rate, sorry?

**Hon NICK GOIRAN:** In the model, from time to time, because we are dealing with humans, not robots, errors will be made. Has your research included any assessment of the error rate in those jurisdictions?

**Prof. WILLMOTT:** The research that I am talking about in terms of the permissive models were of the Australian bills, and it was a strictly legal analysis of the nature of those models, so what you are suggesting is outside the terms of reference of what we looked at.

**Mr S.A. MILLMAN:** The Carter decision that you referred to earlier—the Canadian decision—resulted in the Canadian Parliament passing changes to their criminal statute. For the purposes of the nomenclature, do you describe the Canadian system as a permissive model or a defensive model, because it amends the criminal code?

**Prof. WILLMOTT:** That is a good question. There are two models, as I understand it, in Canada. One is the model that is used in Quebec, which is a permissive model because it has the entire framework around when medical assistance in dying will be lawful. The Canadian model is different to the one that operates throughout Australia —

**Prof. WHITE:** I do not think the fact that in the Canadian model there are amendments to the criminal code makes it a defensive model. I think the situation in Canada is a clear process which is set out which facilitates and permits assisted dying to occur, provided certain criteria are met. In that instance, I would regard that as being very much—if you were grouping in terms of camps, it would be in the permissive group.

**The CHAIR:** Can you elaborate on your reasons for not suggesting a specified time limit or proximity to death to be eligible for voluntary assisted dying?

**Prof. WHITE:** Our position, as you know, is set out in our chapter in the textbook *Tensions and Traumas in Health Law*, but as a starting point, as we noted, we articulated a set of values that we determined could guide us in thinking about what the law necessarily should be. That led us to conclude that to be eligible to receive assistance to die, one should need to have a serious and incurable medical condition that will cause a person's death. There are also other criteria—for example, intolerable or enduring suffering—but the relevant one when we are thinking about time, or an absence of it, is a serious and incurable medical condition that will cause a person's death. This obviously does impose some requirement—a proximity to death. It is not open-ended eligibility.

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The person needs to be seriously unwell and the condition will, in fact, cause their death. We decided not to select a specific time during which a person would be eligible to receive assistance to die, for a range of reasons, including, first, that the values we identified as guiding our thinking did not point to a specified time limit. So, balancing the idea that the importance of life against autonomy and reducing suffering does not magically come up with a point in time of X months or X years from then that eligibility for assistance to die should arise. That is linked to the second point, and that is that picking a time is by definition arbitrary. In recent debates across Australia, we have heard dates such as six months, 12 months, and two years all put forward. There is no reason to preference one date over the other. Thirdly, an arbitrary time limit is also very difficult in practice. A prognosis is notoriously challenging and practitioners have different ways in which they may assess that. So access to assistance to die should not depend on something as uncertain as this.

**The CHAIR:** Can you elaborate on why your suggested guidelines diverge from the UK prosecutorial model?

**Prof. WHITE:** Yes. Perhaps a starting point is to note that we do not think prosecutorial guidelines are the best way to regulate this area. We have raised it as an alternative to consider if assisted dying legislation is not passed or while it is being considered. The model proposed with my colleague Jocelyn Downie is again a values-based exercise. We started by identifying the principles that should govern the exercise of the discretion by the DPP whether or not to prosecute in cases of dying. Those three principles that were identified were: autonomous choice, high-quality decision-making, and public confidence in the exercise of prosecutorial discretion. That led us to publish those proposed guidelines that you will have in your materials in the Melbourne University Law Review 2012. I think the reason why the guidelines that we proposed diverge from those outlined in the UK is because they were very different processes. Ours was a values-based exercise where we articulated what we thought was important and then rigorously applied that to the setting.

This was different from the United Kingdom, where the DPP was prompted by the House of Lords decision on Purdy, where the DPP acted to develop guidelines about how that discretion on whether or not to prosecute would be exercised. That case was against the backdrop of a number of cases it then had to consider, which were really about compassionate, one-off, assisted dying from a loved one, generally by taking them to Switzerland to receive assistance to die there. So those guidelines are very much shaped by that practical setting rather than the first principles approach that we adopted, and indeed the DPP in the UK acknowledged that there was a discussion about whether or not it was a first principles approach, and he said he that had avoided what he called the schematic approach, and that this was very much a practical exercise. That explains that divergence in those two sets of guidelines.

[11.30 am]

**The CHAIR:** There is a suggestion that the law may be improperly intruding into an area that belongs to the authority of the doctor, in the privacy of doctor–patient relationship. Can you comment on whether you think a similar dynamic may play a role in Australia?

**Prof. WILLMOTT:** Thanks for that question; it is a really interesting one, and I thought there was an interesting assumption that underpins the suggestion that the law might be improperly intruding. The assumption seems to be that the authority of the doctor and the privacy of the doctor–patient relationship should be outside legal regulation, at least when the patient is approaching the end of life. I think it is important to unpack that assumption and the implications of that assumption. Certainly the doctor–patient relationship should be confidential and the matters discussed between them should not be disclosed. Similarly, the authority of the doctor in a doctor–patient relationship should be something that is negotiated between the doctor and the patient, and to an extent it is

fair enough to say that the law does not have a role in that negotiation. But there is an important caveat to that. Doctors are not above the law, and they are bound by the law. This is fundamental to the notion of the rule of law, which underpins our democracy, and that is one of the key values that we think needs to underpin the law in this field. The law governs any aspect of medical practice—the need to obtain consent, the duty to use reasonable care and skill, and duties of confidentiality; for example, keeping patient records confidential. In the end-of-life field law governs what a doctor can and cannot do. So, as we have talked about today, a doctor can give medication at the end of life even if that coincidentally causes death, provided his or her intention was to relieve pain and suffering. The suggestion that the law may be inappropriately intruding into the doctor–patient relationship seems to imply that it is okay for the doctor and patient to decide on a particular way forward, regardless of whether that is legally permitted, and if that is what is being implied, that is a concern. There is evidence in Australia that, on some occasions, unlawful activity occurs at the end of life, but we do not know the extent to which that occurs. More research is needed on that, but it is important that the law does regulate what is lawful and what is not, when doctors are treating patients at the end of life, and where boundaries of unlawful practice are drawn are legitimate matters for the law, as a reflection of community values, to play a role.

**The CHAIR:** Submissions to this inquiry have raised concerns that doctors' involvement in the intentional killing of their patients would compromise the patient–doctor relationship. Do you think there is any merit in trying to minimise doctors' involvement in the administration of lethal medication?

**Prof. WHITE:** We start our response to this question by thinking about asking a question, I guess, about the submissions, and we have not read them—can we make that statement—but I guess it is worth considering what evidence underpins those comments and the extent to which that evidence can be regarded as reliable. Without that evidence there would not be any weight for those assertions. Leaving that aside, we do not see a value in trying to minimise doctors' involvement in assisted dying. This is obviously those who are willing to participate in assisted dying. Our proposal, which we have discussed in the course of this discussion, is that voluntary euthanasia and assisted dying where the person themselves takes the drugs, or whether the doctor actually administers the final medication—both should be available. Reasons include the value of autonomy, which we talked about before, which points to the patient having the choice of administering themselves, or having that medication administered to them. We are also considering, for example, those with a disability, who may specifically need another to administer medication. As a wider point, we also anticipate the safety of assisted dying would be enhanced where there is medical involvement and medical supervision. If a suggestion is being made to exclude doctors who are willing to participate from being involved in assisted dying, I think there is a good argument about safety and quality on that point to having medical supervision.

**The CHAIR:** In Switzerland, the intermediary, Dignitas, plays a significant role. Would you be able to comment on any of the advantages or disadvantages of that kind of intermediary model?

**Prof. WILLMOTT:** The Swiss regime is interesting because it has only got one provision which is relevant to assisted dying, so it does not have that full set of models that we talked about earlier. My understanding is that the regulation is a mixture of their penal code, which prohibits assisted suicide for selfish motives, but also other obligations which are imposed on doctors outside the code, as well as some legal obligations. Only doctors can prescribe the relevant drug, and that can only be done in accordance with recognised rules of medical and pharmaceutical practice, and the courts have interpreted that to mean the doctor needs to examine the patient's reasons for seeking suicide, and assess their competence. To go to your question, looking at the detailed body of regulation around the world, it appears the practice is constrained by internal guidelines of



organisations such as Dignitas. I understand that Dignitas does have guidelines, and will not provide assistance unless those guidelines are complied with. However, our view is that it is much more preferable for regulation to be through legislation, regulations and supported by strong policy. That would provide greater community confidence in the regime as well as greater certainty about what is involved and what is not, and a process that must be complied with before assistance to die can be given.

**Hon NICK GOIRAN:** Further to that last question that you were asked about Dignitas in Switzerland, I refer you to a written question that you were given, and also once again the footnote. This time it is footnote 19. It talks there about the system in Switzerland with Dignitas working whereby the employee would fetch the medication from a pharmacy. You will note there that it goes on to say that, generally, a patient never receives the prescription for the medication to take at home. Have you had an opportunity to research the Swiss model, and would you be in a position to advise us in what circumstances the patient would receive the prescription to take at home?

**Prof. WILLMOTT:** I have not researched how the Swiss model operates on the ground, so I cannot answer that question or make a submission on it. I just refer to my earlier comment that I think it would be preferable in such an important matter as this that regulation be governed by legislation, regulations and policy.

**The CHAIR:** I am going to move on to prosecutions. You have expressed a view that there are particular risks for healthcare professionals, but the evidence before the committee is that they have and continue to relieve the pain of dying patients even if it does hasten death. As far as we are aware, however, the first prosecution of a doctor for assisting a patient to die while in the terminal stages of an illness in Western Australia was in 2001. Can you comment on why there have been so few prosecutions in this area, given the apparent constrictions of the Criminal Code?

**Prof. WHITE:** There are two areas in which this risk of prosecution lies. One is where law is unclear, and so attempts by health professionals to practise lawfully may fail, and the resulting behaviour is unlawful or questionable. The second legal risk arises where there is a clear intention to behave unlawfully, for example, providing euthanasia or assisted dying. Based on the question in the material provided by the committee, we understand that this is about the second situation where behaviour that is probably unlawful is not being prosecuted.

[11.40 am]

We have not done empirical research on this point. The views we are expressing are based on our own reasoning and those of others. We note that some argue that at least in some states in Australia there is what some have described as an informal truce or conspiracy between the police, prosecutors and doctors that this will sometimes be tolerated. Certainly the situation of Rodney Syme in Victoria where he has made very clear the actions that he has taken, but there is a real lack of desire to prosecute there. As I said, this is not an area that we have done empirical research upon. Those are observations to be taken on that basis. That said, in these and other debates, arguments are sometimes advanced on the basis that, "Look, if there are not prosecutions we should leave the law alone. It is kind of working as it is; people can get what they need and so on." In our view that approach is untenable on a number of grounds. There are a couple that we will mention. One is the rule of law. The law must be applied and followed consistently by all. As members of this committee would know, as custodians of state law, the proposition at law that things are currently working as is and we should not fix what is not broken, in inverted commas, cannot be accepted—that is not an acceptable proposition. The other objection that might arise here is the value of autonomy. While some people may be able to access assisted dying—there is evidence that this happens—that is obviously available to people who have connections and other

abilities to access and that is not available more broadly. That was just a final observation I wanted to make on that question.

**Mr R.R. WHITBY:** Professors, did you get any indication that this truce or conspiracy is happening in Western Australia?

**Prof. WHITE:** No. As I said before, this is the discussion amongst medical practitioners and others who are writing and working in the field. We have not done empirical research on it. We share that, I guess, in trying to answer the question but we are not aware of anything specific in Western Australia.

**Mr R.R. WHITBY:** It is a general anecdotal belief across the country, though?

**Prof. WHITE:** I would not go that far. As I said—and I am trying to be as clear as I can in terms of when we have evidence of things and when we are trying to, in good faith, share information or discussion that we are hearing anecdotally—it is certainly very much a category of the latter.

**Hon COLIN HOLT:** You mentioned earlier, when we talked about terminal sedation, that it requires consent from the patient or a substitute decision-maker. We often use substitute decision-makers in the provision of palliative care, including close to end of life. Yet in some of the suggestions you talked about the safeguards for a model that could be implemented around competence of decision-making, I assume you mean of the patient in that instance—is that right?

**Prof. WILLMOTT:** Yes. What we are talking about in our recommended model in chapter 26 is we are recommending a regime where only people who had capacity would be able to request assistance to die; that is right.

**Hon COLIN HOLT:** That should not extend to alternative or substitute decision-makers?

**Prof. WILLMOTT:** That is correct. That is what we are suggesting.

**Hon COLIN HOLT:** Why is that?

**Prof. WILLMOTT:** For the reason —

**Prof. WHITE:** We outlined this at the beginning of the chapter. One of the challenges is that we identified the value of autonomy as being a critical part of the values-based approach. What counts as autonomy and notions of autonomy can vary when you are talking about substitute decision-making and someone stepping into the shoes and deciding on behalf of another. For that reason, the proposed model that we put forward does not contemplate a role for substitute decision-makers.

**Prof. WILLMOTT:** We are suggesting that the regime—we think there are fundamental differences between the regime of assistance to die on the one hand where a person should have capacity, and on the other hand what should be legally permitted if a person is at the end of life and has unrelenting pain and suffering, that is a different practice. The practice of terminal sedation is entirely different.

**The CHAIR:** Your research has indicated that doctors generally have a poor knowledge of the law, at least in relation to the withholding or withdrawing of treatment at the end of life for adults who lack capacity. Does it surprise you that doctors are not better informed of the law on these issues?

**Prof. WILLMOTT:** The short answer to that question is no, I am not surprised. There are a few reasons for that. The law on this field, and this field is withholding and withdrawing life-sustaining medical treatment from adults who lack decision-making capacity, is extremely complex and differs across Australian states and territories. We looked at the knowledge of the law in Queensland, New South Wales and Victoria. It is difficult for doctors to know and understand it, and certainly until

relatively recently there have not been a lot of resources available to doctors so they can find out about the law if they need to. That is the first reason—it is complex, and we can be confident that it is complex and difficult to access. The second reason is more speculative. It may be that doctors think that if they are acting in a way that is consistent with good medical practice, that is probably going to be lawful so there is less need to find out what the law actually says. We do not have evidence of that and that is just speculation as a result of this research that we did in terms of doctors' knowledge. The third reason that I am not surprised is our research suggests that in making decisions for their patients, a doctor's own professional views of what is in the patient's best interests matters more to them than what the law says they should or should not do. For those reasons, we are not surprised that doctors do not have good knowledge of the law in that field.

**The CHAIR:** Your submission notes that many of the practices of palliative care are little documented and researched. For such significant medical intervention, this appears surprising. Are you able to elaborate on why this might be the case?

**Prof. WHITE:** There are many barriers to conducting rigorous research to measure end-of-life care and practice. We believe that where it is possible to facilitate this research, that governments, regulators, health bodies and others should try and support this. This is integral to improving end-of-life care and decision-making at the end of life. Some of the key barriers that we have seen in our research and in talking with others include the approach of some research ethics committees. Caution and prudence are critical for research in this area because this is serious and sensitive research. Research ethics committees, rightly, carefully scrutinise proposals to conduct research in this area. But there is a risk, and some research ethics committees may take on a hypercautious, extreme attitude that can block important research in this area. There may be political barriers. Organisations may say, "Look, this is important research. I endorse it. This is something that should happen", but are unprepared to assist or become involved because of the political sensitivity of end-of-life issues. It can be challenging to receive funding for end-of-life research. End-of-life care is not a popular funding topic, for example, compared with a new cure for cancer. That can present challenges in designing and implementing the rigorous research that is needed. Finally, the recruitment of participants to support the research. This is often patients with terminal illnesses, and their families. Research to improve care and decision-making we think must include the people who this is about. We have patients in our care, and patients are integral to inform the research to make sure that care is as good as it possibly can be. It is important to create space and opportunities from those perspectives to shape that research. But finding people who are willing to participate who are obviously grappling with major life issues can be challenging. That said, we should note we have conducted a recent study that involved interviewing a range of people and their family members who are in the middle of making end-of-life decisions for themselves. They were very pleased and appreciated the opportunity to have their say and to try to make things better.

If the law is to change in Western Australia, and indeed some of this does not require law change, but if there is legislation or changes to the law in Western Australia, it would be ideal if that legislation could contain provisions that both permit research and facilitate it happening to support high-quality end-of-life care—research about high quality end-of-life care and decision-making. We also consider that government departments, statutory bodies and officers should acknowledge the importance of this research in this area and assist to step past some of those barriers I mentioned earlier.

[11.50 am]

**Mr J.E. McGRATH:** Going back to your submission, under safeguards, you talk about having oversight by a new retrospective review body dedicated to overseeing an assisted dying regime. Would that

review body look at every case or only cases that are raised with them by a family member or when there is something extraordinary about a certain case?

**Prof. WILLMOTT:** I think that it would be important for any board that is set up by the legislation to be looking at every case and, generally, we would be thinking that if there is assistance to die provided by a doctor, then a report should be made to the board monitoring the practice.

**Hon NICK GOIRAN:** Professors, earlier you were asked about the lack of knowledge by doctors with respect to the law and you indicated that it is very complex and it differs from jurisdiction to jurisdiction. Are you in a position to comment on whether doctors are in need of more training on identifying when someone does and does not have capacity?

**Prof. WHITE:** I think there are two issues there. One is what does the law say on whether or not somebody has capacity, so there is obviously a legal test. The second question is whether or not clinicians need more training on whether or not a patient has capacity. I think you really asking about the second, are you not?

**Hon NICK GOIRAN:** Yes, please.

**Prof. WHITE:** Again, that is not something we have done empirical research on. I guess I would make the observation that capacity is assessed every single day in just about every hospital or health facility around the country. This is a standard part of medical practice. Before any patient is given treatment, their consent is required, so a threshold issue is whether or not they have capacity. I think that is something which is done as a routine, common practice.

**Prof. WILLMOTT:** I would regard the ability to assess capacity by a doctor as part of their core competency, because if they are providing medical treatment to a person who has not consented to it, they are committing an assault. So, I would have thought that that is a core competency that doctors would have. Of course, there are situations in which it is not clear whether a person has capacity. If a person has just been diagnosed with dementia, it is very likely that person will still have the ability to make decisions and will have capacity. By the time that person dies 15 years later, it is unlikely that they will have capacity, and some are in between. It is a difficult call to make, but, for the most part, I would say that it is part of doctors' core competencies.

**Prof. WHITE:** I guess the only other thing I would add to that is experience in reading legal cases where there have been difficult questions of capacity assessment. There are a number of cases where the courts or tribunals have had to deal with the issue of whether or not someone has capacity. Those cases have generally involved, for those difficult cases, prior to coming before court seeking a second opinion, elevating to someone with a particular expertise—a psychiatrist, or a geriatrician in the case of an older person—and a process that sort of elevates where there are concerns or questions about whether or not the person has capacity.

**Hon NICK GOIRAN:** Apart from medical indemnity insurers, would you be able to refer the committee to anybody else who could comment on the error rate of doctors in assessing capacity?

**Prof. WILLMOTT:** I am not aware of where that particular kind of data is collected. An article comes to mind by a professor, Professor Malcolm Parker, who wrote an article in terms of doctors' assessment of capacity in the Queensland context some years ago, but that is the only thing I can think of. As I said, I do not recall, I am not aware of any way that that sort of data is collected in any sort of systematic way.

**Prof. WHITE:** I know the article that Lindy is talking about. That would be useful to look at. I guess an important distinction is what is the capacity being assessed for, because, as we all know, capacity is a decision-specific matter. So, I guess, where you are interested in exploring error rates for capacity, I think it would be interesting to explore error rates for capacity where a decision about

ending life or a life-sustaining treatment is involved, because our experience looking at the case law has generally been that doctors, where there is concern or doubt, have taken steps to either seek expert advice or engage the courts or tribunals.

**Hon COLIN HOLT:** I will follow up on that and just ask: Do you think it extends to substitute decision-makers? So, if the core competency of a doctor is to assess capacity of a patient they are dealing with, does that extend and should that extend to substitute decision-makers? If they have called in the substitute decision-maker, should the doctor be required to assess if they are capable of making a decision on the patient's behalf?

**Prof. WILLMOTT:** Yes, that is interesting point. I imagine this is something which from time to time is confronted by doctors who are dealing with elderly patients. If one of those patients has lost decision-making capacity, it might be for a number of years, the substitute decision-maker is making the decisions for the partner and then if they become frail, I think you are right, that might be an assessment. It might be at some point that neither of those people can make decisions on behalf of the patient. From time to time I imagine that the doctor would have to wonder whether the substitute decision-maker has capacity as well, in which case you would have to go down the list to see who is the appropriate substitute decision-maker.

**Hon NICK GOIRAN:** Professors, you helpfully referred us to this article by, I think you said, Malcolm Parker. Would it be possible after the hearing for you to email us the reference so we could access it?

**Prof. WILLMOTT:** Certainly.

**The CHAIR:** Thank you both very much 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 of evidence. We will write to you and follow up with some of the further references that we requested. Thank you very much for your time today.

**Hearing concluded at 11.57 am**

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