

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
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SESSION THREE

Members

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

Hearing commenced at 12.33 pm

Associate Professor MEREDITH BLAKE

Legal Researcher, University of Western Australia, examined:

Dr CRAIG SINCLAIR

Research Fellow, University of Western Australia, examined:

The CHAIR: Good afternoon. We have Associate Professor Meredith Blake and Dr Craig Sinclair 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 on End of Life Choices. We have here 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 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 proceeding of this hearing will be broadcast live within Parliament House and via the internet. Would you please introduce yourselves for the record.

Prof. BLAKE: I am Associate Professor Meredith Blake from the Law School at the University of Western Australia. I am engaged in teaching and research in criminal law and health law and policy.

Dr SINCLAIR: I am Dr Craig Sinclair from the Rural Clinical School, which is within the Faculty of Health and Medical Sciences at the University of Western Australia. I am based in Albany and I conduct research there, but also on a number of national projects. I just want to note that I am not a medical doctor, but I am trained in psychology, and so my research is in health services and social sciences.

Hon Dr SALLY TALBOT: You are a real doctor, like me.

Hon COLIN HOLT: Any bias there?

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

The WITNESSES: No.

The CHAIR: Before we begin with our questions, do you want to make a brief opening statement?

Prof. BLAKE: I have some general comments that I can offer on the structure of criminal law in Western Australia, particularly the codification process and the way that criminal law is approached in Western Australia. I believe that the schematic approach to criminal liability in Western Australia, which has adopted the Queensland (Griffith) Code, is of relevance to a number of the questions, and I can speak to that if members are interested in hearing that. I do not presume that you do not know it, but —

The CHAIR: Yes, please do.

Prof. BLAKE: As I just mentioned, it is a schematic approach to criminal liability, which means that we do not have the common law concepts of actus reus and mens rea, but, really, it is an elemental approach to criminal liability. For those reasons, the section on criminal responsibility in the code is

of particular importance. We do not read into offences' mental elements. For example, the offence of manslaughter in section 280 of the code states that it is committed if somebody unlawfully kills another person. There is no express reference to any mental element there. The way that liability will often be determined is through the window that unlawfully opens into the sections of criminal responsibility and other defences, such as self-defence. Those sections on criminal responsibility, for example, include provisions on the accident defence, on unwilling act and so forth. It is important to understand that the way that criminal law is approached in Western Australia is through this elemental system, so that those sections on criminal responsibility become particularly important. I might say also that there is no reference to any sort of defence of consent and that the only place where it is specifically mentioned in relation to bodily offences is in the offence of simple assault and aggravated assault, and specifically in relation to sexual assault. Consent to one's own death is specifically irrelevant to liability, as you are probably aware.

The CHAIR: Thank you. I am going to move to our specific questions.

It is a fundamental principle of medical treatment that, except in emergencies, treatment can only be administered with a person's consent. Would it be correct to say that generally, medical treatment is not an offence under section 259(1) of the Criminal Code, which provides that there is no criminal responsibility for medical treatment properly administered for the benefit of that person?

Prof. BLAKE: I think that it is important to understand something about the background of section 259. It was originally part of the code, but early case law was associated with abortion, and it was amended in 1998 to include medical treatments. Previous to that, it only included surgical procedures. In the relatively recent case of Brightwater Care Group against Rossiter—can I presume that you are aware of that case?

The CHAIR: Yes.

Prof. BLAKE: In that case, Chief Justice Martin looked at section 259 and the amendments to that, and they had taken place pursuant to the changes to the Guardianship and Administration Act surrounding advance health directives and the introduction of enduring powers of guardianship, including decisions around end-of-life treatments, specifically withdrawal of that sort of treatment. That section has therefore been broadened and seems to have provided something of a refuge for consent. Specifically, Chief Justice Martin did say that whenever a person has the capacity to make a decision about having life-sustaining treatment withdrawn, then that is entirely reasonable and therefore would be provided with protection under that section. But I should add that Chief Justice Martin did not feel, in any event, that the removal of the treatment would be an offence, because he did not feel that section 262 of the code would apply, and that, of course, is the duty to provide the necessities of life to those who have the charge of people unable to care for themselves. I think that perhaps the position for medical treatment and the non-provision of that has been accommodated within the scope of that provision, particularly now that those amendments have taken place.

[12.40 pm]

The CHAIR: Do you agree that the withdrawal or withholding of life-sustaining medical treatment is likely to be protected by the court's interpretation of section 262, even if a patient or their substitute decision-maker had consented to or even requested it, so long as the doctor in good faith and with reasonable skill assesses it as futile?

Prof. BLAKE: Your question is about the scope of section 262? Which question is this?

The CHAIR: Sorry, I jumped to 4, "Withholding medical treatment".

Hon NICK GOIRAN: Can I just go back to 259.

Prof. BLAKE: Yes.

Hon NICK GOIRAN: I think it can be made available on the screen, although I suspect you probably do not need it. Earlier today in a public hearing we took evidence from some other academics, and it was suggested that the issue of consent is a factor that a court would take into account when determining what is meant by “in good faith and with reasonable care and skill”, so it would be read in when determining what those words mean. Would you concur with that?

Prof. BLAKE: I think if we have a look at the text of the section, which says the administration or non-administration of the treatment, pursuant to those amendments, is reasonable having regard to the patient’s state at the time and to all the circumstances of the case. When we are talking about consent, we are talking about the state of mind of the patient. I think it is important that we appreciate that it is about the patient’s subjective agreement or refusal to have the treatment. Whether or not a doctor acts in good faith and with reasonable care is about the conduct of the doctor, and obviously we can assess whether or not the doctor is acting in good faith and with reasonable care by reference in part to what the patient wants or does not want, but I think it is a larger question. I think that when Chief Justice Martin was deciding the case of Rossiter, he looks at whether or not that non-administration of the treatment is reasonable having regard to the patient’s state at the time and to all the circumstances. The circumstances were that Mr Rossiter had been assessed as having the mental capacity to make that decision by a clinical psychologist, Dr Rachel Zombor, who gave evidence at the court. That was viewed in that case as being the appropriate repository for the relevance of consent or non-consent in that case.

Hon NICK GOIRAN: I appreciate that clarification. It would assist me somewhat if I could just narrow that down. In terms of all the different words in the subsections in 259, is the issue of consent dealt with in those words in contrast to consent being required in considering other aspects or limbs of that section?

Prof. BLAKE: Consent is not expressly included in there. I suppose one of the issues which we need to think about here—this comes down to the code and its schematic approach to liability and the elemental approach—is that, essentially, we do not read into the code provisions unless there is a lack of clarity. The code replaces the common law, so I think that when faced with the situation in the case of Christian Rossiter, Chief Justice Martin, unusually, starts with the common law. That is unusual because the code, as I said, speaks for itself; it seeks to replace the common law. But I think that it was very, very important that the code not be contrary to the very established position in common law, which says if a person has capacity to refuse treatment, even lifesaving treatment or sustaining treatment, that wish should be respected. I think it was unusual, but it does show that starting at that point and then reading those provisions consistently with that position, which is entirely correct. It would be not right if our law was not consistent with all of the other authorities that have come from Canada, the United Kingdom and America. So I think it is a question of reading that section in a way that could achieve the appropriate outcome in that case.

Hon NICK GOIRAN: Is there a case for inserting consent into the section, or would that be unhelpful?

Prof. BLAKE: I think that is a very important question. I think that there are ways in which consent can be approached and included and I think that it forms part of the wider question of how this committee would approach end-of-life decision-making, including outside of the code. So I think that it is a bigger question and I would be happy to put some more thought into answering that question after I have had time to reflect on it.

The CHAIR: Thank you. We are still on section 259. Prior to the amendments made to what was then section 259 in 1998, how would medical practitioners administering medical treatment, as opposed to performing surgery, that risked permanent injury to a patient or death be afforded protection under the Criminal Code?

Prof. BLAKE: There is no specific protection, as we have established. The definition of a common assault under sections 222 and 223 of the code does make reference to consent and the prosecution needs to prove lack of consent beyond a reasonable doubt as part of the prosecution proving its case, but that is common assault. There is also aggravated assault, where an assault occasions bodily harm, where the courts have said that there are some instances of bodily harm which can be consented to, but it would depend upon the evidence put before the court as to whether there was actual consent.

You are probably aware that there is no provision in the code for consenting to wounding or consenting to grievous bodily harm or consenting to death; indeed, consent is irrelevant under section 261. Probably the way in which medical treatment was approached was as something of a policy exception. There is a Queensland case by the name of *Lergesner v Carroll*, in which these policy exceptions are discussed. They include medical treatment where that would, on the face of it, look to cause bodily harm, and, indeed, injuries that are sustained in the course of playing sport. These are policy exceptions that society regards as exempted from the scope of criminal liability where there is the relevant consent in place. But it must be said that with the code having no specific provision to that effect, that has been the purview of the cases—to essentially promulgate that idea.

[12.50 pm]

Mr S.A. MILLMAN: *Lergesner*—was that an assisted dying case?

Prof. BLAKE: No.

Mr S.A. MILLMAN: It is a sports case?

Prof. BLAKE: Well, it is about a fight between two individuals in which bodily harm is sustained, and the question was whether it was sustained with the consent, because it agreed to enter into a fist fight. You will find that there are cases that whilst they are not about assisted dying or even medical treatment, judges take the opportunity to talk more widely about the principles. I think that there are several cases that do this, both in our jurisdiction and notably in the United Kingdom, where for quite a period of time we sought guidance, but we of course have our own laws and our own very developed body of case law. But I think that you will find that you do not necessarily want to confine yourself to certain sorts of cases, because of these ideas about policy exceptions. The broader view as a society is we say people should be encouraged to go and play sport, lawfully within the rules and medical treatment in good faith and so forth is obviously a very good thing. So we want to make sure that our society accommodates that within the legal frameworks.

Mr S.A. MILLMAN: *Lergesner* might be an interesting read because Queensland is a code state as well.

Prof. BLAKE: Correct, yes. In Western Australia, we take decisions from the Queensland courts as akin to precedent, really. If the provisions are the same as what we have, they are not true precedent, in the fact that they are not our courts' decisions, but they are very, very persuasive.

Mr J.E. McGRATH: You are saying that if this committee or the Parliament wanted to progress with some assisted dying, really the consent should not be put in there—it could be put in some other framework?

Prof. BLAKE: As I said, I think that is a very big question. I think we have to understand that there is the code, and we have got guardianship and administration legislation, so this question is a bigger one. If the committee chooses to proceed and consider how it might accommodate the legalisation of some form of assisted dying, we need to give very, very careful thought to a range of legal frameworks. We need to give very careful thought to whether we are regarding it as simply a matter of excluding it from the criminal regime or whether instead we take heed of what has happened in some other jurisdictions, for example in Canada, where assisted dying has now been regarded as a matter for the individual provinces to legislate under their powers to make health laws. We also need to consider whether we want an entirely separate piece of legislation which treats it as a particular contextual issue, as they have done in Victoria. I think that is a very big question that touches several areas of the law. I do not think that simply looking at section 259 and what we can do with that is going to provide us with any real useful solutions. It is a bigger question.

The CHAIR: Would you agree that the withdrawal or withholding of life-sustaining medical treatment is likely to be protected by the court's interpretation of section 262, even if a patient or their substitute decision-maker had consented to or even requested it, so long as the doctor in good faith and with reasonable skill assesses it as futile?

Prof. BLAKE: I think that Craig and I have had, in relation to this question and the couple that are following them, a talk about the use of the term "futility" in connection with these questions.

The CHAIR: I am happy for you to address this subject area as one, rather than going through each question, if that is preferable?

Prof. BLAKE: Yes, I think that would be appropriate.

Dr SINCLAIR: I think questions 4 and 5 come together, in a sense, around this issue, particularly in relation to question 5, that under common law a competent patient can refuse life-sustaining treatment even if a doctor does not consider it futile and would otherwise arguably be under a duty to administer it as a necessity. Both Meredith and myself discussed this and had some queries, I guess, about the conceptualisation of the question, which potentially leads to a dangerous extension that doctors are obliged to administer all non-futile life-sustaining treatments in the absence of a refusal. My personal preference would be that a question like this is framed, firstly, around an elevated or privileging of the doctrine of consent, which therefore identifies the duty of care as not extinguished by the person giving a consent, but to understand what that duty is as the decision is made. The duty of care, therefore, could be to diagnose the deterioration and determine that a life-sustaining treatment is potentially required; and, two, to offer the life-sustaining treatment and obtain consent from the patient or the substitute decision-maker if relevant, except in emergency situations in which the treatment could be administered without consent within the principle of necessity.

The issue of futility, I believe, should be seen as a separate one and not conflated with the concept of consent or the best interests of the patient. As other people such as Ben White and Lindy Willmott have gone into, futility is a complex construct. It has been understood differently in clinical and legal contexts. I believe that the concept of futility should ideally be framed in terms of its objective characteristics rather than linking it with the subjective elements of consent—that is, is the treatment able to achieve its desired functional or biological purpose? From a clinical perspective, the concept of futility, in my experience, is used practically to define a range of treatments that are out of scope for a patient in a particular situation and therefore may not come into the discussion that a clinician has with their patient. An example is that if a person is experiencing multi-organ failure, attempting resuscitation will be futile in that situation. It will not achieve its biological or functional aim. Secondly, futility also provides a framework for clinical decision-making to refuse

treatment, as in clinicians to refuse to offer treatment in cases in which patients or family members might be demanding treatment that is not indicated for their condition and again will not achieve the desired functional aim. Thirdly, to provide a framework for the clinical decision to withdraw treatment at a certain point in time where it has become apparent that the aim is not being achieved through continuing with that treatment.

My point really is that I think if the question is framed around a doctrine of consent and futility is kept as a separate issue, then it perhaps can be judged, if needed, whether the judgement of futility was correct or incorrect, which would perhaps be helpful in clarifying the concepts.

[1.00 pm]

Prof. BLAKE: I entirely agree. I think it is important for the committee to not construct the duty around a criteria of futility and to recognise that consent is about the subjective state of mind of a person, whereas futility, as Craig has indicated, we can regard as an objective criterion. I think it is important that those two are kept separate.

Hon NICK GOIRAN: If a treatment was considered by the doctor to be futile and the patient consented to it, presumably there is no obligation on the part of the doctor to perform that futile treatment. The only option, then, is for the patient to seek out another practitioner.

Prof. BLAKE: Correct. In legal terms often—not often—patients' families may seek to have life-sustaining treatment continued in circumstances where the treating physicians have concluded that it is not in that patient's best interests for that treatment to continue. Where that has been litigated, the courts can then, in their *parens patriae* jurisdiction—that is, where the patient lacks capacity, as has been the case in these sorts of instances—make an assessment as to whether or not that continued treatment is in the patient's best interests. In a number of cases the courts have referred to the term “futility” as one of the reasons for it not being in the patient's best interests. I can refer the committee to the case of *Northridge v Central Sydney Area Health Service*. You may not be aware of that case of a young man who was assessed by the doctors as being in a condition where they regarded it as not in his best interests to continue with life-sustaining treatment. That course of action was challenged by his sister. It went to courts and the courts found in that instance that there was evidence that this treatment was not futile and that, therefore, treatment should be continued. That is an example of a situation where doctors were required to continue treating the patient, despite their views. Essentially, that is the effect of the court order, because the court is saying, “This patient needs to be treated. The conclusion that it is in his best interests to withdraw and withhold that treatment is not correct in our view”, and that is because the court can make its own assessment of what is in the patient's best interest in its *parens patriae* jurisdiction.

Hon NICK GOIRAN: What happens in the case of a doctor saying that as a matter of conscience he or she will not provide that? Does their conscientious objection, if you like, override that court order?

Prof. BLAKE: The law does accommodate conscientious objections. We see it in other areas of medical treatment. For example, with abortion there is a requirement to refer a patient. There is a case from the United Kingdom of *Ms B*, where a woman who had effectively suffered a number of cerebral strokes and was dependent on a respirator was assessed as having capacity to have that treatment withdrawn, leading to her death. The people who were caring for her were not willing to do that. They were very fond of her. They did not want to be involved in removing her from the respirator, so she was transferred to another facility where that took place. When we are looking at these very difficult decisions, particularly when carers are very invested in that person and do not want to be a part of that, we find a pragmatic solution to it. I do not think, necessarily, that we need to look at the law in too much detail if we are finding that this person does not want it anymore,

they have made their decision about that and they have been assessed as having the capacity to refuse it, that wish now has to be respected and we will find a way to do it. That is what happened in that case.

The CHAIR: I will move to palliative starvation and dehydration. Is it useful for you to address the questions as a whole rather than going question by question?

Prof. BLAKE: Yes, it is probably. They tend to bleed into each other. The question that the committee is asking is in relation to palliated starvation and dehydration. Is that correct?

The CHAIR: Yes.

Prof. BLAKE: You have referred us to the South Australian decision in which the court found that the refusal of hydration and nutrition did not constitute suicide. There is an interesting question here around whether or not there is a difference between refusing ANH, which is, of course, classified as medical treatment, and refusing food and water administered through the mouth directly. In my view, it is consistent with the case law to say that refusal of nutrition and hydration is not regarded as an act of suicide. That has been noted in a Canadian case. Indeed, in Rossiter itself, which is a Western Australian case, there is no reference to an idea of Mr Rossiter committing suicide; it was about refusing treatment that he no longer wanted to receive. I personally think that this could be extended to include feeding and hydration that is directly administered orally. I think there is an established view that this is not an act of suicide. I think that more generally there has been a shift in the narrative to avoid referring to these sorts of instances as acts of suicide, and I think that is appropriate.

The CHAIR: In your view, does that extend to artificial nutrition and hydration?

Prof. BLAKE: Artificial nutrition and hydration is clearly regarded in the law as a form of treatment. As there is a right to refuse unwanted medical treatment, that clearly falls within the scope of that. There is a case called *McKay v Bergstedt*, which is an American decision. The court was clearly of the view that this was not an act of suicide, but a case of somebody who simply did not want to be treated in this way any longer. I think it is the appropriate view.

Hon NICK GOIRAN: Every time this topic comes up I always think of anorexia. I would be interested in your comment on whether the distinction between the two revolves around capacity. In both instances, a person is obviously making a decision that they do not want to be hydrated or to take any form of sustenance, but there is obviously a difference between the two and as a community we take a different approach with regard to the two. Is the difference capacity? Have we as a community, or the medical professionals, determined that the person who is diagnosed with anorexia does not have the capacity and, hence, we will force them to be hydrated and sustained?

[1.10 pm]

Prof. BLAKE: That is the approach that the law has taken. A lot of these cases involve minors. The law has taken the approach that the person in question has a misperception of reality which affects their ability to make decisions related to their condition and that this renders the person lacking the capacity to make that decision and then, on that basis, the treatment can be administered without their consent. Of course the infant; you have a duty of care to feed our young children who cannot feed themselves. It is a different question.

The CHAIR: I am going to step back to that question around nutrition and hydration, just to clarify. In these circumstances, would you consider non-artificial nutrition and hydration be classified as a treatment, so no eating and drinking?

Prof. BLAKE: Excuse me; sorry?

The CHAIR: Would you consider the non-artificial —

Prof. BLAKE: Non-artificial?

The CHAIR: Yes.

Prof. BLAKE: No—I was addressing the question of suicide. I was not considering the scope of treatment. I think that feeding a person orally is care. I was addressing the question of whether or not it constituted an act of suicide, not a question of medical treatment. There is the case of Gardner from the Victorian Supreme Court in which that specific issue of ANH was considered. The judge correctly, I think, said the protocols involved the substances involved in the artificial feeding process and the fact that it is an invasive means of feeding all mean that this has to be classified as medical treatment. Clearly, those factors do not apply to the oral administration of food and drink. I understood the question to be around what you would classify as an act of suicide or not.

The CHAIR: We will move on to the doctrine of double effect. Do you want to address us on these questions?

Prof. BLAKE: You will know that the issue of the doctrine of double effect is a doctrine that comes from Catholic theology. It has been utilised in end-of-life treatment scenarios, with the death of the patient being seen as an incidental bad effect, which is coming out of a good course of action, which is of course the relief of pain. It is problematic, I think. I think that we need to be clear that one of the reasons why is the use of the term “intention” and purpose in connection with this. These are terms that the law has struggled to define. Therefore, if the doctrine is relying upon what the doctor’s intent or purpose is, that brings with it other difficulties that are not just about treatment, but indeed wider questions of what intention and purpose means for the purposes of the criminal law. In a way, it is inherently problematic and not just because of how the doctrine might be construed but because it does engage with those other terms that have caused problems of legal definition.

In *Rossiter*, which involved Mr Rossiter asking for the possibility of the supply of water so that his suffering through lack of food was not accentuated, Chief Justice Martin looked at the question of whether or not this could be accommodated within section 259. Of course it seems to have been parliamentary intention to include that situation within section 259. But I think he quite rightly said that it would depend upon the facts of the case, so it is a question of looking at exactly what was administered and the sorts of quantities. I think there is clearly a scope within that provision to accommodate that sort of situation which the principle of double effect appears to try to address or has been applied in those sorts of instances.

The CHAIR: I will go to question 11. Can you comment on some of the views expressed before this committee that the doctrine of double effect is no longer required in the context of appropriate end-of-life treatment?

Prof. BLAKE: That depends upon why there has been a conclusion that it is not thought appropriate. It seems to me that there are two possible reasons for that. The first is that if it is thought that appropriate pain medication does not actually result in the acceleration of death, that seems to me an evidence-based conclusion and would say, “Well, we do not need that because in fact the evidence indicates that actually it does not have that effect.” So that is an evidence-based conclusion. If that is borne out by the evidence, why do we need this and we do not need to have people worrying about it? That view has been expressed in the literature, but there has also been a view expressed by Timothy Quill, for example, that there are a small proportion of people for whom there will be an acceleration of death. If then that is the case, there is evidence that it does have that effect, we need to look at the question of whether or not we resolve that through the

application of this doctrine, which was developed not in the context of palliative care or administration of pain relief but in quite a different context.

Hon Dr SALLY TALBOT: It is not a legal concept.

Prof. BLAKE: It is not a legal concept but it has been adopted. From my readings of the evidence given to the Victorian inquiry, that seemed to suggest that there were still concerns in the medical community about the administration of pain relief. That is what I read from the evidence that was heard there. It is a concern. As I said to you earlier, it is a theological concept. It has been used in deontological theory in moral discourse. Whether it can stand up to the demands as a legal test is questionable and that, for me, is around inherent issues that we have had with the meaning of intention. I must say that I think in Western Australia and Queensland, we now have a fairly clear direction on what “intention” means for the purposes of criminal law through the decision of Zaburoni in 2016. I think we are in a better place in the code jurisdictions than in the common law for which that concept of intention has proven to be quite troublesome.

The CHAIR: In relation to supported decision-making, can you elaborate on the different approaches in relation to this? You outlined some of those in your submission.

[1.20 pm]

Dr SINCLAIR: Sure. My comments in our submission about supported decision-making were grounded in Australia’s commitments as a signatory nation within the United Nations Convention on the Rights of Persons with Disabilities, then the more contemporary inquiries undertaken across Australia by different jurisdictions—Queensland, Victoria, New South Wales—and the Australian Law Reform Commission recently. A prevailing direction in all of these reports has been an acknowledgement that traditional substitute decision-making practices operating with the best-interest test are not satisfactory. The UN convention establishes that people living with disabilities have a right to legal capacity on an equal basis with others in all aspects of life, and that this places an obligation on states’ parties to provide citizens with access to support in exercising their legal capacity. Supported decision-making is the practical end of this convention. It is being promoted as the mechanism by which a person might enjoy legal capacity on an equal basis with others in the context of disability. My comments have particularly come out of the work of our research group, which Meredith is involved in as well, investigating supported decision-making and its role in a range of end-of-life decisions for people living with disabilities, particularly dementia. The supported decision-making paradigm begins by broadening the scope of decision-making, and understanding the capacity to exercise one’s decisions as not existing within oneself alone but within a relational context. It draws on feminist theory, but also just the pragmatic understanding that in order to enjoy any sort of autonomy we enjoy that in the context of social and community relationships. When we look at decision-making through that lens, it actually helped us understand that for a person with a disability the context around that person can be accommodating of them enjoying their legal capacity or not. For someone with a visible disability, the obvious example is a wheelchair ramp for someone to access a space. If that is a cognitive disability it is a little bit harder to maybe define in terms of the physical act, but it is a context or a rigour in the decision-making process. This challenges the bright-line approach to legal capacity that has been established within law, and instead investigates what can be done to promote a person’s decision-making ability.

A number of jurisdictions in Australia have commenced pilot programs on supported decision-making, mostly working with clients with mental illness or intellectual disability. Our work with people living with dementia and their family members has shown that this is also a candidate condition within which supported decision-making could be relevant. Through the interviews that we have conducted with these people they have told us about a number of factors that combine to

deprive people with dementia of their autonomy. I am referring specifically to people with dementia because that is where our empirical evidence comes from. These factors include a lack of understanding and awareness of dementia, and its spared cognitive abilities, among family members, service providers and professionals; cultural assumptions about dementia, which lead to these people being excluded from decision-making about their own lives, usually because service providers are defaulting to informal substitute decision-making processes often among family members; and that our current laws do not require service providers, professionals or administrative tribunals to take all reasonable steps to support a person to exercise their own autonomy prior to using substitute decision-making. I would note in that statement that certainly within the jurisdiction of the WA SAT there is a principle for guardianship to be invoked but it has to be seen as necessary, and that where a guardianship is invoked it is in a least restrictive form; a limited form ideally, and only a plenary form if that is necessary.

While people with dementia and their family members have endorsed these principles of supported decision-making and identified for us a range of strategies in which they are already doing it informally in their own lives, they have also identified that it can be challenging in practice. It is time-consuming, resource intensive, and it can lead to difficult ethical issues of its own as well, particularly those around determining when is the point at which a person who is being supported is unable to make decision even with all reasonable supports. What we have come to through this research is suggesting a number of principles by which supported decision-making could be incorporated within these jurisdictions and where it might exist alongside substitute decision-making, and the principles by which substitute decision-making would occur in order to be consistent with the United Nations' convention. We can provide those in writing if you prefer.

The CHAIR: Yes, that would be helpful.

Dr SINCLAIR: We have a number of papers that will be coming out this year on that point. Obviously the scope of decision-making that we are looking at is broader than just medical treatment, but certainly we see that medical treatment and lifestyle decisions would fit within the scope of this and be relevant to looking at supported decision-making as an area for consideration.

The CHAIR: Can you describe what those informal substitute decision-making processes look like?

Dr SINCLAIR: One example would be when a person is looking at going into residential aged care. There might be some disagreement between the person and their family as to whether that is the right thing to happen at that point. In those cases there are often examples of substitute decision-making occurring in the absence of any formal measures like an enduring power of guardianship. It could be questioned as to whether the person has decision-making capacity at that point. That could be a contested issue. It is a question of what recourse does that person have to other options, and is this an example of their autonomy being eroded in that situation. There are probably more what you might call everyday decisions that are also made that do not operate within the context of medical treatment decisions but yet can still be very meaningful to a person in terms of their lifestyle activities and other aspects of their care—who is visiting them; those sorts of things. Where there is no formal scope for the decision-making, it can occur differently among different care providers or on a cultural basis of practice rather than having a protocol or an understanding of the principles that underpin that.

Hon NICK GOIRAN: Dr Sinclair, this whole area of supported decision-making is really complex stuff. In your submission you make mention of a substituted judgement approach to substituted decision-making. Can you explain that to us?

Dr SINCLAIR: Sure. Meredith might want to add to what I say. One of the big shifts that has been seen in this supported decision-making discourse has been to recognise that there may be cases

where a person's will and preference is not clearly ascertainable and that substitute decision-making is occurring as a last resort mechanism, but where it does occur we are being directed by what is known about the person's will and preference—their subjective either prior directions or what is ascertainable at the time and, in the absence of that, a consideration of their human rights rather than an objective determination of their best interest, which has been challenged particularly within the disability sector. The quote that you might put around that is, "How do you know what my best interests are?" It is that subjective question.

Prof. BLAKE: Substituted judgement is referred to in discourse as stepping into the shoes of somebody else, which people find hard. It is very challenging in itself. There are practical difficulties around that. Training needs to be provided. You cannot assume that you can step into somebody else's shoes and make a decision that they would have made in the circumstances. Substituted judgement has long been a standard of decision-making in the United States of America because of the constitutional due process rights that are enjoyed there. Therefore, the Supreme Court has ruled that when substitute decision-makers are making decisions for somebody else, their first approach should be one of substituted judgement.

[1.30 pm]

The CHAIR: I am going to move to assisted dying. Can you elaborate on why you consider the Victorian Voluntary Assisted Dying Act 2017 to be narrowly framed?

Dr SINCLAIR: The framework for eligibility to assisted dying under this act requires people to have a life-limiting illness with a life expectancy of less than six months, or 12 months in the case of it being a progressive neurological condition, and full legal capacity to execute their own decisions, and advance directives for assisted dying are also explicitly not permitted within this legislation. In the example of someone living with dementia, dementia can be fast in progress or it can be very slow. People can survive 20-plus years with dementia. It is a progressive condition, so people's cognition tends to decline across the course of the condition. For these people, they may foreseeably lack the capacity to make such a decision for that substantial period of time, that 12 months prior to their death, and such an act would not allow them access to this choice.

In my experience of talking with the community about advance care planning and refusal of medical treatment, I have had a lot of discussions with people about their views on euthanasia. It is very interesting how it brings up this issue for many people. In many cases, a lot of people are looking at the issue of euthanasia as something that they would want to pursue to avoid that loss of independence and autonomy that they might experience, particularly in the case of dementia, which has now become, from some recent research, the most feared health condition. It has overtaken cancer as the most feared health condition. I would propose that actually this is underpinning a lot of the community concern and interest in the concept of assisted dying.

As Professor Kathy Eagar commented in relation to the Victorian legislation, it is very narrow in scope and incorrectly frames the matter as a health issue, rather than a social issue. Perhaps this strategy might have been taken as a political compromise, but she also argues that it sidesteps the difficult debate about the real reasons why people choose assisted dying—that it is more often about wanting to maintain independence and control, rather than avoiding severe pain at the end of life. That is what we see from the empirical evidence from people who actually request and follow through on a request for assisted dying.

The CHAIR: Can you comment on the merits of the legislation in respect of patient autonomy and equality in relation to the administration of lethal medications?

Dr SINCLAIR: So my personal perspective on this is that I am supportive of the rights-based approach that is taken in Canada and established in *Carter v Canada*. I believe that an approach grounded in the principles of autonomy and equality of access to assisted dying would be preferential. Within such an approach, the safeguarding that we might think about when looking at safeguarding assisted dying would give its attention to safeguarding the integrity of the decision-making process, rather than providing a criminal defence for the medical practitioner. That would include things such as having access to genuine alternatives—the example being someone in a remote area who does not have access to palliative care; potentially you could say that the decision-making process is compromised in that situation—the ability to withdraw consent; and, rather than having a blanket eligibility criteria such as an expected time of death, to actually be making that criteria around the rigour of the decision-making process and the person's ability to give consent for that at the time. Alongside that, the capacity to execute advance directives for assisted dying would also be consistent with this principle of autonomy.

Prof. BLAKE: I think we both feel that it is important to put the integrity of the consent process front and centre here. Consent is the accepted justification for medical treatment generally. It is only where the person is not able to exercise consent that we then move to the necessity or substituted decision-making framework. Adults are presumed to have capacity. That is the starting point. Legitimation of medical treatment is tied to that model. I think that it is important that we focus on that. It is the model which puts the autonomy of wills and preferences of the person at the front and centre, rather than, as Craig said, trying to construct a defence, which, of course, is the way that it works in the Netherlands. So, this is a rights-based approach.

There is no reason to suggest that the consent process cannot be robustly constructed, and that would include the three elements of a valid consent or refusal, of course, which are the capacity of the person, the knowledge of what is about to take place with the treatment, and I think very importantly, the voluntariness of that decision, and that these three pillars of consent be properly protected. In this realm, I think that there is a lot of talk about capacity and particularly where perhaps mental illness sits with that, but I think also we need to be very conscious of the voluntariness aspect. Perhaps even the model might require the delivery and communication and taking in of certain amounts of information that we may not require in relation to a minor or standard medical procedure—and you can do that.

Hon Dr SALLY TALBOT: Dr Sinclair, I am familiar with the Philip Nitschke criticism of the Victorian legislation, but you just gave us another source there of the person who critiqued it and said that it did not give expression to the full range of concerns. Can you give us that reference, please? I could not find it in your paper. I am not sure whether it is there.

Dr SINCLAIR: No, it was not in the submission, but I elaborated further based on the question.

Hon Dr SALLY TALBOT: Would you be able to give that to the staff so that we can follow it up?

Dr SINCLAIR: Yes.

Prof. BLAKE: We are happy to give more.

Mr J.E. McGRATH: Going on from what you just said, are you saying that the Victorian legislation was more aimed at people with cancer where the medicos could make a better assessment of how much longer they had to live, whereas with dementia they might not be able to be so specific?

Dr SINCLAIR: Certainly prognosis in dementia can be uncertain and it is also often not the dementia itself that eventually leads to the death of a person but other comorbid conditions that are occurring at the same time. My concern is that a framework that is answering the concerns of a part of the community but is not providing access to what is going to become a very large demographic of our

community is potentially problematic. I am coming at this from the point of view of my concern about the rights to access to making decisions about one's own life and to supporting those rights—in this case in the context of assisted dying, but it would also apply in a number of other decision-making contexts as well.

Mr J.E. McGRATH: Thank you.

Hon NICK GOIRAN: I have just made a note that I think I heard you say that three pillars of consent need to be properly protected. Did I get that right?

[1.40 pm]

Prof. BLAKE: Well, I was not reading off my notes. I suppose that was just a term that I use. But when we talk about the elements of a valid consent or a valid refusal, we talk about whether or not the person has the capacity; people are presumed to have it, but there may be instances when questions are raised around that and there is a test.

This all is related to the work on supported decision-making, because capacity, as it stands, is a legal bright line: you either have it or you do not. Supported decision-making is challenging that bright line to say, "Well actually, if you're given the right supports, we can help you to make the decision that you really want to make", rather than just applying that bright line. That is the first thing. The second thing is that the person has a basic level of understanding of the procedure or therapy. The third thing is that the person executes it voluntarily. There is a quite famous case from the UK where a young woman decided to refuse in advance a blood transfusion after spending an hour in her hospital room with her Jehovah's Witness mother. Essentially, the court said, "Well, there are these things in life that can have a coercive effect on our decision-making; one of them is our family and the other one is faith", and they regarded her decision as not a voluntary one in that sense because they felt she had not had the opportunity to make it herself. That is what I mean by those three elements—perhaps "pillar" is not the right word—because there is a degree of relationship between the three. At the end of the day, consent is an ethical concept. We talk about it as a legal term, but consent is an ethical concept. It is about whether the person has expressed their own wish, if this is what they want. When we talk about signing forms and so forth, all we are really talking about is evidence of it. A signed form is not a consent. This is why we want to emphasise that consent is a subjective concept. It is whether that person has taken in that information free of influence, has thought about it and has come up with their own preference or will. I find the consent form culture problematic, because it is thought that a signature is it, and it is not. We have to remember that consent is, at heart, an ethical concept about the expression of one's own autonomous wishes.

Hon NICK GOIRAN: So, consent is a subjective matter. How, then, as a community do we make an objective assessment on whether the person has given consent, given that it is subjective?

Prof. BLAKE: As I said, consent has long been the basis upon which we regard even standard medical treatment as being justified and right and proper and so forth. When we are talking about how we can feel satisfied, that is where Craig and I were referring to the robustness of the process. We cannot climb inside another person's mind and look and see, "Did they or didn't they?" What we can do is we can have transparent frameworks. We can have safeguards. We can have ways of best practice and ways of demonstrating that, with this evidence, we can feel comfortable that this person has the capacity to make this decision, has received all the appropriate information and understood it, and has made this decision free of undue influence. That is all we can do, really, because we cannot climb into somebody else's head.

Hon NICK GOIRAN: You referred to the UK case where I think you said the court found that it was not free and voluntary because of the one-hour conversation and other various elements. What was the outcome in that case for the patient?

Prof. BLAKE: When somebody is treated without their consent—in this case she was given the blood transfusion—there may be a challenge to that, and that is based around the laws of trespass; the touching and interference with bodily integrity without consent. If that is litigated, then the question will centre around those questions: Did the person have the capacity? Did they receive the appropriate information and understand it? Did they make the decision voluntarily? In fact, in that case, *Re T*, the court found that the refusal was invalid for two reasons. One was that there was evidence that she had been unduly influenced, so it was not a voluntary refusal; and the second was that she had not been given what was regarded as vital information about the effects of not receiving the blood transfusion. So for two reasons, the court was prepared to find that it was not a valid refusal.

Hon NICK GOIRAN: So in that case there was not true consent?

Prof. BLAKE: It was a refusal.

Hon NICK GOIRAN: A true refusal.

Prof. BLAKE: It was not legally valid.

Hon NICK GOIRAN: But there was an opportunity after the event for a court to intervene and fix the situation?

Prof. BLAKE: It happens because the person who feels that they are wronged and are the victim of a trespass then litigates against it. This happened in the Canadian case of *Malette v Shulman*, you may be aware of, where a Jehovah's Witness woman who received a blood transfusion brought an action for trespass against the hospital, and was successful in that instance.

Hon NICK GOIRAN: So how important is it, then, as a safeguard that a person who may be wronged is in a position to seek redress?

Prof. BLAKE: What sort of scenario are you —

Hon NICK GOIRAN: In this situation there was somebody who was wronged, I think I heard you say, and they were able to effectively put in a complaint or to litigate and have that wrong fixed.

Prof. BLAKE: Well, they can be compensated, yes. In *Malette v Shulman*, I believe it was \$Can20 000. It is not fixed in the sense that it cannot put her in the position that she would have been in, but it is the way that the law addresses those sorts of claims.

Hon NICK GOIRAN: She had the blood transfusion in the end?

Prof. BLAKE: She was given it, yes.

Hon NICK GOIRAN: Which originally she had said she did not want.

Prof. BLAKE: She had a clear note on her person which explained her faith and that she entirely understood the consequences of not receiving the blood transfusion.

Hon NICK GOIRAN: Was she complaining that she had it or —

Prof. BLAKE: She was alleging a trespass. She was alleging that she was treated without her consent, as an action in civil law, a tort.

The CHAIR: Just back to the Criminal Code and section 259, is it problematic to include the justification for assisted dying within a provision of the Criminal Code, section 259, where a patient's consent is not required?

Prof. BLAKE: When you say “where a patient’s consent is not required”, are you referring to a situation where the person is lacking the capacity to make the decision, or has not expressed it?

Hon NICK GOIRAN: Sorry, can I jump in? I think the problem with this question is that it is going back to the earlier point about section 259 and perhaps a different view amongst some as to whether consent is in or not. But I think you have already clarified for the committee, based on Chief Justice Martin’s review of section 259, that consent is a factor in the consideration of it.

Prof. BLAKE: As I said, section 259’s history and the reasons for its introduction are different from its subsequent interpretation and expansion as a result of the amendments in 2008 and the 2010 provisions that allow us to make advance health directives, EPGs and so forth. I have written an article on the Rossiter decision in *The University of Western Australia Law Review*—I do not know whether I have referred to it—but I do look at the history of section 259 and the way it is used in the Rossiter decision. The expression I used in that paper was that it is a refuge, because there is no other place conceivably in the code to accommodate this, and that is the place where it can be accommodated. I want to emphasise, though, that Chief Justice Martin, when he was deciding whether or not the Brightwater Care Group had a duty to administer the necessities of life to Mr Rossiter, he concluded after consideration that they did not, because that particular section was designed to protect people who had the charge of others who could not take care of themselves, and because Mr Rossiter had been assessed as having capacity, this he felt could handle it. But then he said that in the event that it does not, or in the event that there is disagreement about that, as a second argument he would find that his consent provides a justification under section 259; so it was the second part of his reasoning.

[1.50 pm]

Hon ROBIN CHAPPLE: I would like to go back. Dr Sinclair, you were talking about people with dementia and they being un-availed of situations in terms of voluntary assisted dying. It is an interesting one, because many doctors have indicated that the definition of a terminal illness is attributed via time. A doctor can say, “Over a certain period, I know that this person is going to die.” I think everybody is going to die at some stage, so we can make that assumption. When it comes to people with dementia, we know that it is eventually terminal. I think the issue that most probably concerns me is that, with dementia, if it is, say, a long three, four or five-year process, medical intervention may be available at some stage in the future. Therefore, I am intrigued how you deal with dementia and those sorts of things in a voluntary assisted-dying capacity. Can you give me some more thoughts on that?

Dr SINCLAIR: Okay; sure. I think there are two parts to that. One is the longstanding debate about the experiential and critical interests of a person, in this case with dementia, but it could be any range of ongoing cognitive impairments where they have expressed a preference clearly stated at one point in their life and at a later time in their life they are acting differently; they are acting in ways that make it seem that their prior directions are no longer reflecting who they are now or what they value or are in their experience. That idea of their critically reflective directions that they might have given with full consent and full capacity in the past, having to be weighed against this person whose cognition has changed and is acting in different ways that now draws into concern what is this person’s actual experience right now and they seem really happy now, so would they still want that advance directive to refuse treatment to be applying in this situation? That has been debated for a long period of time in the ethics literature. I think Meredith is probably much better qualified to discuss that.

Prof. BLAKE: Dworkin has argued about that.

Dr SINCLAIR: But in this case of assisted dying, I think the issue that keeps coming up for me is that necessity to give consent or to take the action at the time of the assisted dying, and would a person with dementia who has reached that point in their trajectory of their dementia be able to do so on an equal basis with someone who has perhaps a more physical disease? Another example you could think of is someone, perhaps, who had a completely locked-in syndrome where they could not act physically to administer a lethal dose of medication. There are problems that I can see around the issue of a consent that is required at the actual time of the act, which may leave some people less able to utilise the provisions that are there.

Hon ROBIN CHAPPLE: So you are seeing it as a negative in the process instead of a positive? I am trying to put it that way. So you are seeing it as people who possibly want to access voluntary assisted dying being denied; is that your —

Dr SINCLAIR: That was the way that that scenario played out then, but I imagine that it could run in the opposite direction as well. In the example of a person with severe and profound dementia, I think it is one thing where in our project on supported decision-making we have been certainly quite wary of very serious decisions. Will-making would be an example. Assisted-dying decisions would be another one where when a person is in that state where their capacity is contested, how do you actually satisfy yourself that they are meeting the criteria for giving that consent at that time?

Hon ROBIN CHAPPLE: So you are seeing it as a double-edged sword, really?

Dr SINCLAIR: I can see it being problematic from both points of view.

Hon NICK GOIRAN: On page 9 of your submission, you do what I call give the committee some homework. You basically say that we need to consider the issue of assisted dying and that the committee is fully aware of the implications of the different models that have been adopted in those jurisdictions, which are legalised forms of assisted dying. Are you able to tell us how many models there are?

Prof. BLAKE: I can do that, yes. I think part of this is addressing question 16, which is the prosecutorial guidelines in the UK. We have models in the Netherlands and Belgium, which are based around a necessity defence. It came from the case law and it was legislated for, I think, in 2000. This is based around the position of a physician who has been put in a very difficult position—the patient who wants assistance in dying or a lethal injection and the other duty which the physician has in relation to maintaining the health and life of the patient. So it is derived from that. There is the model in Switzerland, which you may be aware of, in which assisted suicide is not a crime unless it is done for malicious reasons, or selfish reasons I think is the term that is used. So that is a different model again. Then you have got the models in the United States of America. The states have leeway to introduce those. We have now got about, I think, eight states in the United States of America. These are physician-assisted suicide models and these are, I think, the legacy of Supreme Court litigation around physician-assisted dying—the Glucksberg and Quill Supreme Court litigation—in which the substantive due process rights in the Bill of Rights were used to argue that the crime of assisting suicide was breaching the Bill of Rights. It is the same argument that was used in the Roe v Wade decision. So there is that.

Then we have the model in the United Kingdom, which is not a substantive change of the law but was a result of litigation in two cases—the case of Diane Pretty and then Purdy, where they were challenging, again, the crime of assisted suicide by reference to article 8 of the European Convention on Human Rights, which has been adopted into domestic UK law through the Human Rights Act. That litigation resulted in a finding that article 8 did include a right to make decisions about the controlling and timing of your death. It has not changed the law, but the challenge to that in the Purdy case meant that the DPP was then told to put down some factors as to what would be more

likely to result in a prosecution and what would be less likely to result in a prosecution. Interestingly—I am not sure if this has changed—when I last looked at it a factor in favour of it was the involvement of a physician; whereas, a factor against it was the involvement of a family member. That brings up the familial model of assisted dying, about which there is quite a significant narrative as well.

We have different models out there and I guess what I would say as a point of conclusion is that there are different ramifications for those models. I think that if we put forward a model that is based around autonomy, is based around the expression of wills and preferences, that is a different model from a model based around necessity, and I think that that is unlikely to be palatable. I think that we do need to remember that in the Netherlands there is a cultural issue here—the way that the doctor–patient relationship is regarded.

That is talked about extensively in a book written by a professor at King's College London, Penney Lewis, who has written a comparative study of all the different models. She explains that much better than I could, so I will provide you with that reference. I think that you will find it explains the practical ramifications of the different justifications for it. We need to consider all those things. We also need to consider that in Canada, of course, they have a model now in which the Supreme Court has made its decision and has said to the provinces that they have to introduce laws so that these sorts of cases are not prosecuted. That is very much based around the Canadian Charter of Rights and Freedoms. We need to remember that we do not have such a charter; we do not have imbedded human rights. I have always looked upon the litigation that took place in the UK and Canada, and in *Glucksberg* and *Quill*, as providing a hanger for those arguments so that they when they go to court, they can say, "Look, we've got this right", but we don't have those hangers. I think the committee needs to remember that and bear in mind the different cultural norms that apply in different jurisdictions and not just assume that this model is right for us, because we are our own place and our own jurisdiction, with our own laws and Criminal Code, and our own feelings and views about what is acceptable and not acceptable. I think that it is important to bear those differences in mind. That is what I was saying in that piece.

[2.00 pm]

The CHAIR: We have reached the end of our time today. I want to thank you for your evidence before the committee. 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 the 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. Should you wish to provide additional information or elaborate on particular points, please include a supplementary submission for the committee's consideration when you return your corrected transcript. We will write to you about those extra references. Thank you very much today.

Dr SINCLAIR: Can the questions that were not covered be dealt with as a separate supplementary submission?

The CHAIR: Yes, you can send them as a supplementary submission. That would be great. Thank you.

Hearing concluded at 2.02 pm
