GUARDIANSHIP AND ADMINISTRATION AMENDMENT (MEDICAL RESEARCH) BILL 2020

Time Limits — Statement by Leader of the House

HON SUE ELLERY (South Metropolitan — Leader of the House) [11.37 am]: I advise the house that the maximum time limits for each stage of the Guardianship and Administration Amendment (Medical Research) Bill 2020 will be: second reading, 180 minutes; Committee of the Whole, 180 minutes; adoption of report, five minutes; and third reading, 45 minutes.

Second Reading

Resumed from 1 April.

HON AARON STONEHOUSE (South Metropolitan) [11.38 am]: The Guardianship and Administration Amendment (Medical Research) Bill 2020 is an ethical minefield—it really is. Currently, if a person is incapacitated, a guardian or their next of kin may make decisions regarding medical treatment, but that does not extend to participation in medical research. This bill seeks to address that in some way by allowing guardians and next of kin to make decisions in the absence of the consent of a patient about medical research. However, making such decisions is really fraught with danger. After all, who determines which relation has the best interests of the patient at heart? When a person has not completed an advance health directive or has not appointed a guardian, the bill prescribes who is a person responsible for making decisions in the following priority —

> the patient's spouse or de facto partner if that person has reached 18 years of age and is living with the patient; … the patient's nearest relative who maintains a close personal relationship with the patient; … the person who has reached 18 years of age and is the primary provider of care and support to the patient but is not remunerated for providing that care and support; … any other person who has reached 18 years of age and maintains a close personal relationship with the patient.

I have some issues with these categories and will explore them in Committee of the Whole House. The last category—any person who has reached 18 years of age and maintains a close personal relationship with the patient—gives me the most concern. My reading of that is that it implies that a friend or close acquaintance could make decisions for an unconscious patient and opt them into medical research and experimental treatment. That decision may be made in the best interests of the patient but we are really starting to stretch the definition of "guardian" and "next of kin". I have some very close friends but I might be a little concerned about a third party determining which of those close friends was best placed to make a decision about what experimental treatment I may or may not have conducted upon me. Thankfully, when there is an advance health directive about medical research, that directive must be followed. Following the directive is mandatory, and that gives me some comfort. Patients who are concerned about certain types of medical research or experimental treatments can make an advance health directive—this is my understanding—spelling out what type of treatment or medical research they would or would not like conducted on them, if any at all. However, this bill goes further. It allows medical practitioners to make decisions when a patient is incapacitated and the guardian or next of kin cannot be contacted within a specific time frame. The second reading speech states —

> If a person requires treatment urgently to save the person's life, prevent serious damage to the person's health, or prevent significant pain or distress, and it is not practicable to obtain a research decision from a research decision-maker within an appropriate time frame, the bill permits a researcher to carry out research approved by a human research ethics committee. However, this can occur only if an independent medical practitioner has determined that a person is incapable of making reasonable judgements about research for themselves, and if an independent medical practitioner has determined that the research is in the best interests of the patient, or is not adverse to the interests of the patient by increasing his or her medical risks.

That gives me some concern. It is assumed that the guardian or next of kin has the best interests of the patient at heart. They know the person somewhat intimately and know the person's values and are able to make decisions in their absence, to some degree. I am not so sure that a medical practitioner is best placed to make those decisions in the absence of a guardian or next of kin. There are more than mere medical considerations to consider. There are cultural and religious considerations and some people may find certain types of medical treatment abhorrent or incompatible with their lifestyle or cultural norms. In those cases, a medical practitioner is not best placed to make decisions. This discussion is very difficult because a medical practitioner has a moral obligation to act to save someone's life, at least in that moment. That is why I say that we are wandering into an ethical minefield. A classic moral dilemma is when someone is trapped and unconscious in a burning car and, although you cannot obtain their consent to pull them out and take action, you have an obligation to try to help them. Doctors are in the same position. I am concerned about the degree to which the medical research or experimental treatment can be directed towards treating a person's ailment and about who is best placed to weigh the risks, especially if research, or experimental

treatment in this case, could result in lifelong symptoms for the patient. That person's life may be saved but their quality of life following that treatment may be severely diminished. When the treatment comes with some risks, that certainly complicates the decision, and when dealing with an incapacitated patient, that decision is further complicated. My understanding of what we are dealing with in this bill is that it refers to not only unconscious patients, but also patients who are incapable of making a decision. We could be talking about medical practitioners making decisions about experimental treatments for someone with a mental illness in the absence of a caregiver, guardian or next of kin. That should cause some concern. I do not want to live in a state in which, in the absence of a guardian, carer or next of kin, doctors can make decisions about the type of treatment—perhaps experimental treatment—given to people with a mental illness who cannot give consent.

The government has rushed ahead with this bill in response to the COVID-19 outbreak we are experiencing; however, I keep hearing conversations and talking points about the advancement of medical research as a long-term general goal. I want to be absolutely certain with this bill that the advancement of medical research as a general goal does not override the duty of care that medical practitioners have to their patients. In fact, I am somewhat concerned to hear that medical research is one of the primary objectives of the bill rather than saving someone's life by giving them lifesaving treatment that may be at the trial stage in that immediate moment. Ensuring that an incapacitated patient suffering from COVID-19 symptoms is able to receive the best quality care with the consent of their closest relatives is an urgent matter to be considered and is the kind of measure that should be expedited. However, addressing the supposed deficiencies in the Guardianship and Administration Act 1990 to facilitate medical research in the future is something that the government should introduce as a separate piece of legislation and allow the Parliament to fully consider rather rushing ahead with this bill. In fact, the government itself has said it that has not had an opportunity to comprehensively consult on this bill. The second reading speech states —

> The state government recognises that due to the urgency presented by the coronavirus, consultation on the bill has not been as comprehensive as we would like. Consequently, the review clause … will enable the amendments to be reviewed, with wide input from medical and consumer stakeholders, to ensure the policy intent of the amendments are workable on an operational level.

There is no mention of unintended consequences, and that is what concerns me. This bill was introduced into the Legislative Assembly yesterday at around midday and was passed by 5.00 pm. It was then introduced into the Legislative Council. We have had less than 24 hours to consider the bill since it was introduced into this place. I have had no opportunity at all to consult the community on this bill. My time has been taken up with other emergency legislation, all of which I am responsible for, and I have had no opportunity to consult with the stakeholders, aside from the briefing provided by the government, and I thank it for that. I have had an opportunity to hear from only one side on this issue.

I am concerned that the government has not limited the scope of this bill to the COVID-19 outbreak either by limiting the provisions to the treatment of COVID-19 only or introducing a sunset clause so that the provisions cease to have effect after the outbreak is contained. That begs the question: is this about addressing COVID-19 and therefore it should be expedited through Parliament with limited scrutiny, or is it about introducing provisions that the government sees as important despite the COVID-19 outbreak? If they are two different things, they should be dealt with separately. The latter, which is introducing provisions that the government would like to see considered as important despite the COVID-19 outbreak, would necessitate a deeper level of scrutiny than this bill is receiving.

It has been put to me that a sunset clause would be impractical because it would make it difficult for researchers to obtain grants, as they may be issued over longer periods than a proposed 12 or 24-month sunset clause. I do not think the ability of researchers to obtain grants should override the obligation that Parliament has to properly scrutinise legislation, especially when we are dealing with a bill as difficult as this one that deals with consent and doctors making decisions about experimental treatment and medical research in the absence of consent. Aspects of this bill might be genuinely needed right now for this outbreak. I am still trying to get my head around most of the clauses in the Guardianship and Administration Amendment (Medical Research) Bill 2020; it is a very complex piece of legislation. But the lack of scrutiny should cause everyone concern. It is absolutely imperative that we include a sunset clause in this bill—whether it is going to be for one, two or more years can be worked out through further debate during the Committee of the Whole House. We are really rushing ahead blindly here as most members have not had a chance to properly scrutinise this legislation or to consult. Even the government has not had a chance to consult. The government recognises as such by saying that it will conduct a review. That ought not be sufficient for the Legislative Council. It has been suggested that the Education and Health Standing Committee, a lower house committee, would be a suitable committee to review this bill. I do not think that that is the case. The Legislative Council should be satisfied that this bill will get an appropriate level of scrutiny only if there is, firstly, a sunset clause, and, secondly, a review of this bill conducted by one of the Legislative Council's standing committees or perhaps a select committee. We should not abdicate our responsibility to a standing committee of the other

place; that is not how we go about business. We should be entirely satisfied through our own processes that this bill has received an appropriate level of scrutiny.

As I said, we will have to deal with some very difficult ethical questions in this bill. We will not be given the opportunity to flesh them out. We have just over an hour and a half remaining on debate for the second reading so I will not labour the point, but the Committee of the Whole House —

Hon Sue Ellery: Two and a half hours.

Hon AARON STONEHOUSE: We have two and a half hours for the second reading debate.

Hon Sue Ellery: It is nearly three hours.

Hon AARON STONEHOUSE: Yes—two hours and 45 minutes. During Committee of the Whole House, I will be ensuring that this bill gets proper scrutiny—and if not now, at least at a later stage.

HON NICK GOIRAN (South Metropolitan) [11.51 am]: I would like to speak on the Guardianship and Administration Amendment (Medical Research) Bill 2020, and I indicate at the outset that I am not the lead speaker for the opposition. I have been instructed that I have a maximum of 40 minutes to speak and I assure members that I will be complying with that direction.

Some bills are more memorable than others. Next month, it will be 11 years since I was first sworn into this place and, without a shadow of a doubt, this bill will be one of the most memorable bills that I have had to deal with. I say at the outset that I am disappointed and distressed, yet I am supportive of the bill that is currently before the house. That might sound peculiar, but, thankfully, I have just under 40 minutes to explain how it is possible that an 11-year lawmaker can be both disappointed, distressed and supportive of a bill.

I will start with why I am supportive of the bill. In order to do so, it is important that members who have had precious little time to consider this important piece of legislation—as outlined by Hon Aaron Stonehouse very eloquently—and who swore an oath to serve the people of Western Australia, understand the current state of the law in Western Australia on the provision of standard and conventional medical treatment. One of the most fundamental aspects of that is that informed consent is provided by a patient. The absence of informed consent being provided by a patient gives rise to, amongst other things, a medical negligence claim against the doctor who performs the standard and conventional medical treatment without the informed consent of the patient. It is the case under existing Western Australian law that in certain circumstances, what is described as a "substitute decision-maker" can make a decision on behalf of another person. I will use myself as the example. If I am in hospital and I lack capacity—perhaps I am unconscious or for any other reason I lack capacity—I cannot provide informed consent for the treatment that the doctor might want to provide to me. But under the existing law of Western Australia, those doctors will then first ask themselves, "Has this patient got an advance health directive?" In my case the answer is no. They will than ask, "Has this person granted an enduring power of guardianship?" In my case the answer is no. They will then embark upon the hierarchy of substitute decision-makers starting with my spouse, my wife. They will go to her and ask her to consent to the standard and conventional medical treatment. If my wife is unavailable, they will go to one of my adult children. If they are unavailable, they will then go to one of my parents and so on and so forth. It then goes on to siblings, and then carers, of which I have none. If all else fails, under existing Western Australian law there is a capacity to go to the State Administrative Tribunal and engage the Public Advocate. That is the state of the law at the moment in Western Australia.

The problem that the government has correctly identified is that this existing arrangement is not broad enough to capture non-standard treatment. I can indeed make the case for a substitute decision-maker making a decision on behalf of a patient for non-standard treatment. Again, I will use myself as the example. If I am conscious and have capacity, and if a doctor gives me all of the information and I decide to take the risk and say, "Yes, I'll proceed with the non-standard treatment", that can already happen under existing Western Australian law. But if I am unconscious and do not have capacity, under existing Western Australian law that non-standard treatment cannot be provided. That is one of the things that the government is trying to fix by way of this bill and it has my support. Why? It is because I have no difficulty with them embarking on the existing system—for example, going to my spouse and asking her, "Would you like to have this non-standard treatment provided to your husband?" That is what this bill will allow. For those reasons, I am supportive of that element.

Why is it that am I distressed about the matter before us at the moment? In order to understand that, we need to understand the context. On Tuesday last week, 24 March, it was drawn to my attention that a temporary order was proposed to be invoked by the Legislative Council—a truly extraordinary temporary order. A draft of that was circulated to me on Tuesday, 24 March. Members are already well aware of, pursuant to the contribution I gave earlier this week, my views on that temporary order. The following day, I was alerted for the first time about the name of this bill that we are considering now—not the bill itself; just the name—the Guardianship and Administration Amendment (Medical Research) Bill 2020. It is a curiously titled bill. I received that in the context of being advised

the day before a battering ram–styled temporary order was being proposed. The following day on Thursday, 26 March—exactly one week ago—I received a briefing note containing this comment —

> … the Bill authorises the enrolment of incapacitated persons in research without consent …

The instant I read that, I thought to myself, "Are we seriously considering using a battering ram to bring in a Frankenstein-style bill that would allow for research to be conducted on a human being in Western Australia without their consent?" That was the extent of the provision of useful information in the briefing note of last Thursday. The government then organised a briefing, and I thank my learned friend Hon Michael Mischin, the shadow Attorney General, for facilitating that for members of the opposition. That briefing took place on Monday, 30 March. At 3.42 pm on Monday I was provided with a draft bill in readiness for a briefing that was going to take place via Zoom at 4.30 pm. The version of the draft bill that I was provided on Monday at 3.42 pm was version 14. It might interest members to know that the last version that I have seen—remember that was on Monday—is version 21. I hasten to add that the briefing that took place via Zoom on Monday was very worthwhile, and I thank all participants involved in that very extensive briefing, which, from recollection, took more than two hours. During the course of that briefing, participants read to us a letter from Hon Wayne Martin, QC, urging us to support the bill. Curiously, the version that Mr Martin had seen was version 10, and we were being urged to support version 10 of the bill. I emphasise to members that the version currently before us is version 21. Indeed, for reasons I will explain in a moment, it is in fact more than 21. What is further curious about that, is that that letter that was provided or read to us during that briefing via Zoom on Monday was dated 28 March. The briefing took place on 30 March. Within those two days of the letter, four further versions of the bill had been prepared that we were being urged to support.

The following day, on Tuesday this week, two days ago, as members will know, the house decided to uphold the battering ram temporary order. Yesterday, Wednesday, 1 April, at 10.24 pm, this bill was provided to this house. It might interest members to note that at the bottom of the bill before the house, it is marked 176–1B. What does "1B" mean, members? It means that an amendment has been made to the bill, not by the other house, but a clerical error that was picked up on the journey as it transpired from the other place to us here. Let us be clear: we were being asked and urged to support version 10 of the bill. That letter was drafted by a person with a very eminent legal mind on Saturday. By the time Monday came around, we were on version 14. The last version I have seen is version 21, and now I find that there is a version that the Legislative Assembly has not seen. That is the one that we are debating at the moment under these battering ram conditions. Perhaps members of this place, members of the research community, whom I respect, and members of the medical fraternity, whom I respect, can understand why in this context members of this place might be distressed about how this is being handled. In fact, I am beyond distressed about this; I am utterly disgusted by what is happening. This is no lawmaking process whatsoever. It is cavalier and reckless. I ask whichever minister is going to respond —

Hon Sue Ellery interjected.

Hon NICK GOIRAN: Do me a favour, Leader of the House; do not plead COVID-19 as the urgent case for this bill whilst in the next breath opposing a sunset clause. I will have more to say about that later.

The question I ask the house today is: where are the great champions of autonomy? At the end of last year, people were banging on month after month about the importance of autonomy for Western Australians and that, above all, patients must have the choice to do things when it comes to so-called medical treatment and the like, even if it includes taking their life. Why? It is because autonomy is king. Where are these champions today, I wonder? Will they speak out on this bill, or will they be muzzled?

I indicated at the outset that I am supportive of the bill—I am distressed about the bill, particularly the cavalier, reckless process that is taking place—but I am disappointed. Why am I disappointed with this particular bill? It is because I have had a longstanding interest in the Guardianship and Administration Act. For members who are not aware, a statutory review was undertaken under the stewardship of the previous government. It was tabled in, or at least its date is, November 2015. For those who have a copy available, they will see at the end of that statutory review a large list of persons who submitted to the statutory review. I am one of those individuals. Let it not be confused that this is somehow a belated interest by me in these matters currently before the house. These are matters that I submitted to my friends in government in 2015. Indeed, I note for those members of the Western Australian Labor Party who might care to have any interest whatsoever in this bill that is being rammed through today, that they might be interested to know that the late Hon John Kobelke was one of the people who made a submission—a truly honourable man whom I had the privilege of knowing.

In addition to my longstanding interest in this particular act and any amendments and reforms made to it as far back as 2015 when, as a humble backbencher, I was prepared to submit information and put it on the public record for my colleagues in government, members will be aware that I also chaired the Select Committee into Elder Abuse in this Parliament, the fortieth Parliament. I moved a motion, as I recall, in September 2017 and had the honour of chairing

that committee with three other hardworking members of this house. We tabled our report in September 2018. Again, for any member who might care about these things, they might like to familiarise themselves with the work that was done by the four members of the select committee, which we agreed was important to form, and the staff, all resourced by the Legislative Council. They might like to familiarise themselves with chapter 7 of the report, which sets out matters pertaining to powers of attorney and guardianship. I quote briefly from the introduction in chapter 7, which says —

> The misuse of Enduring Power of Attorney … and Enduring Power of Guardianship … documents has emerged as a significant theme during the Committee's inquiry into elder abuse in Western Australia.
>
> The hidden nature of elder abuse and the lack of a register of enduring documents means that abuse can continue for many years, often increasing in severity, with no outward signs to indicate that an EPA is being misused. The Committee has heard that some banks and other financial institutions have established internal procedures to try to identify the signs of financial elder abuse that may occur even where a valid EPA exists for a customer …
>
> There are risks inherent in an older person using an EPA to give a trusted person the power to make decisions on their behalf. Despite this risk, the Committee is of the view that, with the improvements recommended in this chapter, the documents are an effective tool to delegate decision-making in some circumstances.
>
> This chapter will discuss the role of the Public Advocate in elder abuse situations. The Public Advocate is the statutory office holder with responsibility for investigating cases where an adult with a decision-making disability may be at risk of abuse. This role includes inquiring into the potential misuse of EPA … The Public Trustee also has a role in the protection of the financial assets of an older person who may be experiencing elder abuse …
>
> This chapter will also discuss improvements that can be made to the current EPA regime and the importance of the statutory review of the GAA that was undertaken in 2015.

The committee spent considerable time in its report unpacking all the elements pertaining to the Guardianship and Administration Act. It describes what enduring documents are in Western Australia and how a person can apply for one. Specifically, it refers to enduring powers of attorney and enduring powers of guardianship. At the end of that analysis, the committee states at finding 39 —

> Witnessing requirements outlined in the *Guardianship and Administration Act 1997* can be improved to provide more robust protection for an older person who creates an Enduring Power of Attorney or Enduring Power of Guardianship.

Recommendation 20 is that the government review the witnessing requirements set out in the act with a view to strengthening the protection for donors of enduring powers of attorney and enduring powers of guardianship. The committee goes on to talk about the different roles and similar responsibilities between attorneys, administrators and guardians. The committee spent some time looking into the jurisdiction of the State Administrative Tribunal, which will have a role in the matters that are set out in the bill before us. Members of the committee will recall that we visited the State Administrative Tribunal and had a discussion with the president about those issues.

The report sets out on page 80 the problems with enduring powers of attorney and seeks to educate the people of Western Australia and members of this chamber about when the Public Advocate or Public Trustee intervenes in matters. The committee noted also that there is no penalty when an attorney misuses an enduring power of attorney. One of its findings was that the State Administrative Tribunal could be given jurisdiction to hear claims for compensation for the misuse or abuse of a power of attorney. It recommends that the government review the act with a view to giving the SAT jurisdiction to order compensation for the misuse or abuse of a power of attorney.

The committee states at finding 41 —

> The creation of an offence for a donee of an enduring power of attorney who does not comply with their obligations in section 107 of the … *Act* … will help prevent elder abuse that may occur from the misuse of enduring documents.

Recommendation 22 on page 84 of the report is that the penalty in section 107 of the act that currently applies only to a breach of section 107(1)(b) be expanded to apply to the entirety of section 107(1) of the act. The committee indicated that there are problems with the revocation of enduring powers of attorney and that it is indeed the case that more than one enduring power of attorney document can exist. It states at finding 42 —

> The lack of a procedure in the … *Act* … for revoking an Enduring Power of Attorney creates opportunities for elder abuse, an administrative burden for agencies and confusion for older people who may wish to revoke an existing Enduring Power of Attorney.

The committee went on to look at Landgate's register of EPAs for land transactions. It found that the system used by Landgate for registering EPAs in relation to land transfers is inadequate and leaves older people who have such documents vulnerable to financial elder abuse. The committee recommended —

> Landgate urgently review its processes for registering land transfers where an Enduring Power of Attorney is lodged with a view to increasing the safeguards in place to ensure that only one valid and current document may be registered against a land transfer per individual.

For the purposes of today, if members read nothing else in the report of the Select Committee into Elder Abuse, they should read page 87, and particularly paragraphs 7.61 to 7.64. There the committee pauses during the course of its one-year inquiry to consider the statutory review of the Guardianship and Administration Act 1990, the one to which I referred earlier that was prepared in November 2015. I quote briefly from paragraph 7.63 of the report —

> Given the length of time since the review was completed and the relevance of some recommendations to elder abuse, the Committee wrote to the Attorney General in April 2018 to query the status of the recommendations. The Attorney General advised that the Government supports 77 of the 86 recommendations contained in the statutory review, with nine recommendations not supported.

I pause there for a moment. I wonder whether members are aware how many of the recommendations are being implemented by the bill that is currently before the house. Before anybody answers that question, I quote from paragraph 7.64 of the committee's report at page 87 —

> The Attorney General —

Let us be clear about which Attorney General we are talking about here: it is Hon John Quigley, the Attorney General of Western Australia under the McGowan government. I continue —

> also advised that a bill to amend the GAA was approved by Cabinet in December 2017 …

Again I pause to advise members that if they have been tracking the course of these drafts that have taken place, they will see that the date that these things were first approved by cabinet is indicated on the back of the drafts. This one was December 2017, so clearly we are talking about one and the same thing. The committee quotes from the Attorney General, Hon John Quigley, and says, pursuant to the letter that he sent to the committee, dated 26 April 2018 —

> 'it is anticipated that the Amendment Bill will be introduced in the Spring session [of Parliament]'

This was referring to the spring session of Parliament in 2018. Spring 2018 has long gone. So has the entire calendar year of 2019. We are now at the start of 2020 under what I have referred to as corona season, and now is the time that a bill has been brought before the house. Does the bill do any of the things that the committee recommended? Does it do any of the things the government said it supported with regard to reforms of the Guardianship and Administration Act? The committee was misled when it was told that those things would be addressed when Parliament resumed. At the time the committee noted that at the adoption of its report, which was in September 2018, no bill to amend the act had been introduced into Parliament. That was the case, certainly with the Legislative Council, until late last night, when this bill was provided to us. As I say, it must be at least version 22.

At page 87 of its report, the Select Committee into Elder Abuse talks about a register for enduring powers of attorney. We found that there was broad support in Western Australia for the creation of a state-based central register of enduring powers of attorney and that such a register would be an effective means of reducing the potential for financial elder abuse to occur. We made a recommendation that the government investigate the viability and time frame for creating a Western Australian central register of EPAs, with a view to integrating it with any national model that may be agreed to in the future.

The Select Committee into Elder Abuse went on to deal with the issue of undertakings that are provided by private guardians and administrators and made a recommendation that the government amend the Guardianship and Administration Act 1990 to include a requirement that private guardians, attorneys and administrators be required to sign an undertaking with respect to their statutory responsibility and obligations. The committee concludes its consideration in chapter 7 of the report by dealing with the important issue of supported decision-making, not to be confused with substitute decision-making. Findings 45 and 46 conclude that element of the report. Finding 45 states —

> Supported decision-making is an effective means of empowering older people in Western Australia to take control of their decisions wherever possible and enable them to preserve their inherent dignity and autonomy in later life.

Finding 46 states —

> A good way for older people to protect themselves from elder abuse is to plan ahead while they have capacity and make arrangements for later life using Enduring Powers of Attorney, Enduring Powers of Guardianship and Advance Health Directives.

I indicate, as I said at the outset, that I am bitterly disappointed that I and the Select Committee into Elder Abuse have been grossly misled by this government over the course of the numerous debates that this chamber has had when considering the committee report, particularly given that Hon Alison Xamon, Hon Kyle McGinn, Hon Pierre Yang and I, amongst others, regularly contributed to the consideration of that committee report. When I asked a repeated number of times for somebody within government to let us know what is happening with reforms to the act, I was met with disdain and silence. It is in that context that the Guardianship and Administration Amendment (Medical Research) Bill 2020 has been brought before us, supposedly for consideration as serious lawmakers under these battering ram conditions. Perhaps some fair-minded members will understand why, in that context, I am bitterly disappointed and distressed by what is taking place here.

I am actually disgusted by what is happening, yet I remain supportive of one of the key elements of this bill, which is to extend the scope of the decision-making that can be made by a substitute decision-maker to allow for the provision of non-standard medical treatment. Of course, as we know from the briefing note, the bill also refers to a person's enrolment in research without their consent. It is appropriate for the house of review to consider that with cool heads and appropriate time and resources. What is not appropriate is for the government to bring in something like this and give the Legislative Council less than 24 hours to consider it. No doubt people will be following this debate and it is probably worth them noting that the ordinary custom and practice of this house is that a bill sits on the table for a week—we have had less than 24 hours. That is in the context of what I said earlier. We had been told by the government that the bill would be coming in and that the bill, which the government said had been approved by cabinet as far back as 2017, was going to deal with a raft of issues—in fact, a majority of the issues arising out of the statutory review—and yet we got this instead. This bill goes beyond giving the power to traditional substitute decision-makers, such as a spouse, adult children, parents, siblings and, indeed, the Public Advocate under the authority of the State Administrative Tribunal. Given that this bill goes beyond that, with non-standard treatment and what has been referred to in the briefing note provide by the government to members as "experimental treatment"—they are not my words, but words from this government—and the enrolment of people into research without their consent, perhaps it is appropriate that the Legislative Council pause and consider that for a moment.

We all know—it is abundantly clear as the clock continues to count down—that that is not going to happen because the government has said so and there are no other available mechanisms to deal with this situation. We know that the excuse that the government will provide about this disgusting, cavalier and reckless lawmaking process—which has involved multiple members being misled by the government across multiple years with regard to the reforms in this area—is that this will happen in any event, and it is for those reasons that I associate myself with the comments made by Hon Aaron Stonehouse who earlier called for the implementation of a sunset clause. If in this situation the government wants to show any sense of pride in how lawmaking should be properly done in Western Australia, it will not resist the suggestion of a sunset clause. But if it wants to act in a cavalier and reckless way, it will not agree to a sunset clause. It will just bring in this serious piece of legislation in the context that I have just shared with members, ram it through and get it done today without a sunset clause and in all good conscience be proud of its efforts today.

I conclude by indicating for the reasons that I have outlined today that overall this bill has my support, but it should be passed today only with a sunset clause. In addition, I call on this government to once and for all come clean about the reforms it is proposing to the Guardianship and Administration Act. If it is the thing that is before us now, which we were told was approved by cabinet as far back as 2017, I promise members that we, and the committee, have been misled by the government, and it has happened on multiple occasions over the last few years. I ask the government to come clean about those reforms. It may well be the case that the government will say, "We don't have the time to outline to you today what our plans are for further reforms" and no doubt the government will use COVID-19 as its excuse about why it cannot do that, despite the fact that it said that this matter had been considered by cabinet at the end of 2017. It decided to tell that to the standing committee and in response to the standing committee report as tabled in this house. It may say all those things—so be it—but on the next occasion when the house convenes, which I understand is scheduled for 12 May, it would not be asking too much for somebody within government to rise and give a brief ministerial statement that outlines the government's plans to reform the Guardian and Administration Act, which has been addressed in the statutory review of 2015 and by the Select Committee into Elder Abuse, and very little of which has been addressed by this significant piece of legislation.

HON MICHAEL MISCHIN (North Metropolitan — Deputy Leader of the Opposition) [12.30 pm]: I am, indeed, the lead speaker on behalf of the Liberal opposition on the Guardianship and Administration Amendment (Medical Research) Bill 2020. I indicate that the opposition supports the principle of the bill. It supports many elements of the bill, has reservations about some, and had additional reservations about other pieces of it, which have, fortunately, been addressed by the government over the past week since we have had notice of this bill being introduced on an urgent basis as, allegedly, a COVID-19 measure. We have had some extraordinary proceedings over the last several days and bills that ordinarily would have been the subject of considerable scrutiny have been passed on good faith, albeit, sometimes with improvements, in order to ensure that the government can address this crisis. This is said to be one of those measures but, instead of putting politics aside in order to ensure that the public interest is served, as many parties here have, we have been served up with yet another bit of politicising by the government. I will go into a little of the history of this. I wholeheartedly support the observations that were made by Hon Nick Goiran, and I have noted and agree with the observations made by Hon Aaron Stonehouse on this matter.

This is the sort of bill that goes well beyond what it purports to be founded on. It deals with issues of considerable ethical concern. Last year we spent a great deal of time—weeks and weeks—arguing over the Voluntary Assisted Dying Bill 2019, which would allow patients to exercise their personal autonomy in order to decide how they would end their lives with medical assistance. It was based on personal autonomy. This bill extends to people who do not have personal autonomy having their fate decided by medical practitioners and researchers. People who cannot exercise a choice will have that choice given to a so-called independent expert and a researcher to decide how they will be treated. More importantly, it is not only treatment that may be innovative and non-standard to serve their purposes, but also might be, as an adjunct to that treatment, medical research in the broadest sense. The government wants to wave this through in three hours! Last week was the first we had any notice of a guardianship and administration amendment bill, curiously, including "medical research" in the title. It was only on the Friday afternoon that I found out what the substance of it was, but I did not have a copy of it. It was only on Monday evening that I saw a draft of the legislation. It was only yesterday that I received the second reading speech—only a matter of an hour before it was introduced into the Legislative Assembly as an urgent bill.

I want to thank the advisers. I thank the Solicitor-General and his assistant for the time taken to engage in videoconferencing with me, my colleagues, and members of the Nationals WA in respect of us understanding this legislation. I also thank, in no particular order, Ms Jessica Evans; Ms Morena Evans, from the Attorney General's office; and Ms Subhan Dellar, who have been very cooperative and have given whatever assistance they can. But even they are constrained in providing the assistance that we required. Yesterday, we were promised additional information—just a comparison table of what is happening in other jurisdictions so that we know whether this bill goes beyond what is currently in place in other jurisdictions in Australia. We still have not received that, yet we are expected to pass this bill on good faith. Yesterday, we asked a number of questions. They were not about those who have advocated for and support the bill in one iteration or another—they will not have seen the final version—such as advocacy groups on behalf of researchers and institutes and the like, but those who may have put up an opposing point of view or raised concerns. We do not have that information.

This is the sort of bill that ought to be maturely considered by the Parliament and by this house before it goes any further. This bill goes further than addressing the COVID-19 problem—much further! It will be in force presumably for as long as has the 1990 version of the Guardianship and Administration Act, until someone does something about it if things are going wrong. We would expect to have some frankness on the part of the government, but it cannot help itself. The second reading speech as it was delivered here yesterday and in the Assembly states —

> In 2015, a statutory review of the Guardianship and Administration Act 1990 recommended that the legislation be amended to enable a person responsible to make a decision on behalf of a person, for that person to participate in medical research, including treatment that is part of research, in certain circumstances, including if it is in their best interests to do so, considering the risks involved, human research ethics, and other factors. The statutory review was tabled by the Liberal–National government in 2015, but no action was taken to implement the recommended legislative amendments to the Guardianship and Administration Act 1990.

This is deceit by way of half-truths. I refer to that report. It is a statutory review of the act that was tabled in November 2015, a year before Parliament was prorogued for the election. I challenge the proposition that no action was taken on that, but I also point out that the recommendations to which the second reading speech refer were only two out of 86, and those two did not meet what is being claimed in the second reading speech. This is material to the extent that the bill departs into other areas from what is being put forward by the government, and justified by way of the review.

Amendments to the Guardianship and Administration Act were recommended. The report states —

6.1 That in addition to treatment decisions, a decision may be made on behalf of a person, including a represented person, for that person to participate in medical research, including treatment that is part of research when:

- it is deemed to be in the person's best interests
- the research will not involve any known substantial risks to the participants or if there are existing treatments for the condition concerned, will not involve material risks greater than the risks associated with those treatments
- the research has been approved by a human research ethics committee

and consideration is given to:

- the wishes of the person, so far as they can be ascertained
- the nature and degree of any benefits, discomforts and risks for the person in having or not having the procedure
- any other consequences to the person if the procedure is or is not carried out
- any other prescribed matters.

6.2 Health professionals acting under the urgent provisions in sections 110ZI and 110ZIA will not be permitted to make a decision on behalf of a represented person for that person to participate in medical research, including treatment that is part of research.

That is not what the second reading speech claims. Another important feature of it is the Public Advocate. Members should bear in mind that the Guardianship and Administration Act is focused on the care of people who cannot care for themselves under the auspices and control of the Public Advocate, who is their advocate and looks out for their interests. At the time, the Public Advocate stated —

> The Public Advocate supports the concept of a guardian having the function to allow a represented person to participate in such trials, however the wellbeing of the represented person must be the primary focus and consent should only be given where it is clear there will be no detrimental impact on the represented person and in all likelihood they will benefit from participation in the trial. If a trial includes a participant receiving a placebo rather than active treatment, it should not be possible to consent as such a trial could result in the represented person receiving no treatment which could not be seen to be in their best interests and would therefore not accord with the principles of the Act.

Yet the definition of "medical research" in the bill includes the administration of pharmaceuticals and placebos—never mind all that! We have had some briefings, and I thank Professor Daniel Fatovich for his input on medical research. I am more comfortable with the idea of placebos being wrapped up in that for a variety of reasons. As I understand it, a placebo has a psychological bias for not only the person receiving it, if they are conscious—this bill deals with people who are not conscious, of course, so it cannot affect them—but also the administering practitioner. I accept that. I also accept that non-standard medical treatment to assist a patient who cannot give consent, just like with a patient who can, may go beyond the treatment and have a research element to it—it is exploratory to a degree. I accept that there is a need for a broader definition and that it be embraced in this bill. However, the problem I have is the same as that raised by Hon Nick Goiran. We are talking also about non-traditional substituted decision-makers for the patient, who are said to be independent and operate within an ethical framework and who can give consent on behalf of someone who cannot do it for themselves.

Among the many tweaks that have been made to the legislation, one concerns the issue of advance health directives. That, fortunately, has been addressed; they not only have been given paramountcy as a consideration, but are now binding under the bill. That is one improvement we managed to achieve behind the scenes in the time available to us. There are a couple of other tweaks about terminology such as urgent treatment and the like. A few other changes and refinements were also made, including the insertion of a review clause. The original suggestion was for a review not only every two years, but also to roll through periodically at two years. I see now that the government has incorporated a one-year review and at every three years thereafter, and I commend it for that.

The real problem we have with this bill is that we have not gone through the implications. We do not know what the Public Advocate, for example, thinks. We have been told that the Public Advocate has changed her opinion on it over time. I do not know that; I have not seen anything to that effect. No-one in this house, not even those on the government benches, I suspect, has seen evidence of what people generally, including those with an interest in this, think about this bill and the provision to allow substituted decision-makers to engage in research that may go beyond the treatment of the patient and the patient's interests. I am sure we will be told that all researchers are entirely ethical and do the right thing. I have no doubt that most do, but if that were the case, we would not need

a prohibition specifically on electroconvulsive treatment, nor would we need a provision in the legislation to make it an offence to sterilise a patient against their will. So do not tell me that there is not a need! The fact that we have ethical frameworks at a national level and ethical committees in each institution speaks of the need for care in this area. The idea of having someone's fate decided by an independent expert troubles me. What next? Will this be in the voluntary assisted dying legislation as well—an independent expert will decide whether someone's life is viable or whether they would like to be put out of their misery? This should be considered by a parliamentary committee and, in due course, when the legislation passes, as I suspect it will in one form or another, I will move an amendment to provide that a committee of this house—my current thinking is that it will be the Standing Committee on Legislation—be charged with the responsibility of reviewing the legislation that we will pass today and in the context of the Guardianship and Administration Act to see what the opposing and other views might be and whether improvements can be made, rather than doing it in this overheated atmosphere that we are currently engaging in. I hope that the government will support such a measure.

Another amendment that I propose to move will seek to insert a sunset clause, but not over the bill generally. I understand that others might have sufficient concerns to want this bill to be properly reviewed by Parliament rather than it being dressed up as a COVID-19 measure, yet going well beyond it. My amendment will be more targeted. It will focus on proposed section 110ZS, which deals with the non-traditional substitute decision-maker—the independent expert decision-maker. The sunset clause will come into operation after four years. We are told that for the interests of medical research and the like, most funding, to the extent that it is relevant, is for three to five years. I accept that there may be issues with that. I have picked four years because that would allow ample time to see how the legislation works, it would overcome the current crisis and it would allow things, such as traumatic injuries, to be attended to with other treatments, quite apart from COVID. It would also be after the first statutory review had begun, and which would hopefully be finished by then, but in case it was not and work was still in progress, it could feed into the consideration of proposed section 110ZS. With a parliamentary committee looking at this in the meanwhile, it could also feed into that statutory review and the consideration of whether this proposed section or other bits of the bill generally need to be fixed in some way. It would not only provide parliamentary oversight, which we should be having now with our responsibility to the public generally, and personal autonomy, but also meet the needs of patients.

I entirely support the idea that people who cannot give consent because they are incapable should be able to avail themselves of not only standard medical treatment, but also the benefits of innovative and non-standard medical treatment within an ethical framework. However, if this will be in the hands of someone the patient does not know and has no connection with and that person makes decisions on their behalf because it is convenient or they cannot get hold of the next of kin, it raises significant personal liberty and personal autonomy issues—the sorts of things that ought not to be passed without mature and proper consideration.

I will move those amendments in due course, and I would be surprised if they created some insurmountable impediment to the government, given that the operation and integrity of the legislation will be maintained. These are simply measures to ensure that at some point this Parliament does its job on behalf of the people who have elected it and that there is a proper balance. I hope that I can get the government's support for them.

I am sure there will be a number of questions during the Committee of the Whole stage; it will be a truncated Committee of the Whole stage. I accept that we need to do something, but it has been pointed out that despite the high talk about how the last government did nothing, this bill has been sitting around since December 2017 and the catalyst for it being introduced as an emergency measure in such an overheated environment is, I presume, the government's faux pas—I am not going to suggest laziness, but who knows. I know that there were far more important things, such as expunging homosexual convictions, for which there has been one application and that was dismissed because there was not even a conviction. I know that the no body, no parole legislation did not change things materially. I know that all those things were far more important to the government, but this is also important. My amendments will ensure that the legislation is looked at properly, that the other 66 recommendations from the review in November 2015 are addressed and that the bill gets the scrutiny it deserves and warrants, while at the same time enabling the government and those in the medical profession to do what they need to do under the conditions that we are currently operating under.

The Parliament will also be able to look at what is happening in other jurisdictions. We do not know. We were told, for example, that New South Wales was in the process of passing an amendment to its act, but I do not believe it has been passed and we do not know its content. I understand that Victoria has passed the equivalent of a medical research bill. It seems to me that the more controversial measures in this bill for non-traditional consent ought to be in a standalone medical research bill, not be grafted onto the Guardianship and Administration Act, which has a wholly different purpose. I believe that bill has just been passed in Victoria, but we do not know how it is operating or whether there are any concerns about it, let alone what is happening in other jurisdictions.

We do not know to what extent we need to recognise the national guidelines in the bill. We do not know whether deaths that occur during this research will automatically be looked at by the coroner—some might and some might

not. We do not know what level of accountability there will be, although, fortunately, as a result of a suggestion I made last week, the government introduced a reporting provision through the minister to Parliament. Whether that needs to go further to provide more specifics so we are assured that these measures are not being misused is another question, but at least there is some level of accountability now. We do not know what level of reporting and record keeping will be needed.

If the government and members support the substance of the bill at this time, I very much urge them, if they have any regard for their constituents, to include a mechanism in the bill to ensure that the most contentious and controversial provision in it will come to an end unless the Parliament allows it to continue. Of course, those who are engaged in research should have no concerns at all about an extension. If after the one-year review, the parliamentary committee and the way this bill and its provisions are implemented are beyond reproach, those engaged in research can be confident that a Parliament will, in the interests of the public, continue what has been put in place if it is shown to be operating properly. If they do not like that, alarm bells ought to start ringing because that means that there is something they are concerned with that will not satisfy the elected members of the community in four years' time.

I will end my comments there. I will be interested to hear the comments of other members; otherwise, we will deal with the detail of the bill. Hopefully, there will be ample time to address any matters of concern in Committee of the Whole. This bill sets a bad precedent for legislation to be enacted during an emergency that goes beyond addressing the immediate problem and yet can be put on the statute book indefinitely, and may affect the autonomy and civil liberties of a group of patients who cannot, by definition, advocate for themselves.

HON CHARLES SMITH (East Metropolitan) [12.52 pm]: I rise to make a brief statement in the time we have left before lunch. I, too, like some members in the house, am a little distressed at how the Guardianship and Administration Amendment (Medical Research) Bill 2020 is being forced through Parliament. However, unlike the opposition, I will not be supporting the passage of this bill. I feel that the ethical considerations surrounding the bill are enormous and deserve far greater examination than we can give in these emergency sittings.

In a nutshell, the bill introduces the ability for those in WA to be, in effect, guinea pigs for medical testing, which we are told is being pushed to try new treatments for a new strain of the coronavirus. Personally, it is like reading a modern-day retelling of a tale from Mary Shelley. What are we, Madam President? Are we now modern-day gravediggers robbing fresh corpses for experimentation? Is that where we now stand? I do not oppose medical research with consent when it comes from competent and capable decision-makers; however, I note the issues on how objective or reasoned a decision may be in the current climate of fear and uncertainty.

My main issue with the bill is that decisions will fall into the hands of guardians for those unable to make decisions themselves—a guardian who, most likely, is extremely close to the patient and would undoubtedly seek to allow any possible treatment to save a loved one, and may feel some degree of urgency with this new pandemic. My prime concern is that it is not the patient's decision to have this treatment; it is the decision of another person. Such is the issue with guardianship. However, we are now enabling the most vulnerable people to become guinea pigs for new testing through decisions made in quite possibly a split second by a party that may feel pressured to make a decision in the affirmative. I note that there are attempts to create safeguards. I fear that they are just as porous as the voluntary assisted dying safeguards. Given that so little is known about the new strain of coronavirus and the treatment of it, how would a doctor realistically know whether this testing is in the patient's best interests or whether that person would consent should they regain the ability to do so? Similarly, in my opinion, the role of tribunals may perhaps be useless given how rapidly a person's health can turn, unless cases are expedited, which I have not seen in this legislation. In my view, we are getting dangerously close to infringing on the liberties of people who are unable to make a decision. We also do not know what pressure a guardian may feel or be placed under. Given how quickly this legislation is being rushed through, even with the best intentions, I fear that it may have serious consequences for the rights of the individual. At the moment, I do not know how many more of our civil liberties we may be about to lose.

HON COLIN HOLT (South West) [12.57 pm]: I rise as the lead speaker for the Nationals WA on the Guardianship and Administration Amendment (Medical Research) Bill 2020 and indicate our support for it. That support is based on the extraordinary times in which we find ourselves. There are some qualifications behind that support, mainly based upon the process in which we find ourselves. I do not want to reiterate all the debate that has occurred to date, except to say that the Nationals support the bill. We realise that in these extraordinary times, we need every tool available to our medical fraternity to address the COVID-19 pandemic and what it might present in the future for Western Australians.

This bill goes beyond the COVID-19 crisis, as has been well canvassed by other speakers to date. We understand and support the need for urgent medical research. The second reading speech focused a great deal on the response of the government to the COVID-19 pandemic and the resulting crisis. Everyone would support the bill if it focused just on research for that outcome and if we had the ability to say that once the crisis was finished, we would look

at the bill more fully. That was the process recommended in the 2015 review, the iterations of the bill—at this point, we are up to draft 21—and through consultations that some of us have been privy to, but which some of us have not and this house has not.

We support the bill because we see it as a necessary move to allow as much research as possible to occur in this state. However, as others have flagged, it is about the process of how we got to this point. Like others, I think I received a copy of the bill at 1.20 pm on Monday for a briefing that occurred at two o'clock. Under normal circumstances, no-one in this house would say that that is adequate. As lawmakers in a house of review, no-one can accept that that is adequate, but we are not in normal circumstances, as was flagged and commented on in the second reading speech. That is also the reason we are here this week for this extraordinary sitting under the temporary orders.

The bill is narrow in scope; maybe in reply, the Leader of the House can respond to that narrowness. It is about alternative decision-makers for those patients who are incapable of giving permission to consent to medical research.

Sitting suspended from 1.01 to 2.00 pm

Hon COLIN HOLT: I will summarise where I got to before the lunchbreak. We all recognise that the Guardianship and Administration Amendment (Medical Research) Bill 2020 is an extraordinary bill that has been brought in during extraordinary times, and, certainly, we all want medical research to occur in the current circumstances if there is an opportunity to treat people with COVID-19. The extraordinary thing about the bill is that it goes beyond the COVID-19 crisis in which we find ourselves. Everyone in this house would agree that under normal circumstances, Parliament would spend a lot of time reviewing, debating and asking questions about the application of a bill of this nature. I am sure that under normal circumstances, this chamber would, and should, send this bill to a parliamentary committee to be properly scrutinised to ensure that there are no unintended consequences and that it meets the government's objectives in the form in which it has been presented. But we are not in that situation. Obviously, the lead-up time has been shortened and, as far as I can ascertain, we are up to draft 21. The minister is on the record as saying that it is not a perfect bill. Under normal circumstances, that would be a signal to this house to say, "We need to send it to the legislation committee or a committee of this house to do proper scrutiny." The Nationals WA would prefer that a sunset clause be added to the bill to cover these extraordinary circumstances and that such a sunset clause would apply to the whole bill, but the indications are that that will not be supported by this house, so we have no intention of moving an amendment to that end. We will certainly support the amendments that are flagged on the supplementary notice paper.

I refer to the component of the second reading speech that stated that there would be a 12-month review clause. I have heard it said somewhere—perhaps the Leader of the House can confirm this—that there will be a ministerial review, but there is some talk of a commitment by the government to send it to an established committee. I do not know what that commitment looks like. The Nationals and I would certainly prefer that it be sent to a parliamentary committee rather than a ministerial review. Under normal circumstances, a bill is sent to a committee before it is passed, but it looks as though we are committed to passing the legislation with the fallback position of sending it to a parliamentary committee after it has been passed. There has been an indication from members in this house that they would like to see that.

It is unfortunate that this is where we have got to. If the scope of the bill was narrowed to just the COVID-19 response, we probably would not be having this debate, but it goes beyond that. The nature of the bill signals that it needs to be properly scrutinised but, obviously, given the circumstances, the Nationals will be supporting the bill.

HON ALISON XAMON (North Metropolitan) [2.05 pm]: I rise as the lead speaker for the Greens on the Guardianship and Administration Amendment (Medical Research) Bill 2020. I note from the outset that although the bill has been presented as an urgent COVID-19 bill, its substance has been the subject of quite a bit of discussion since 2015; indeed, much of what lies within the content of the bill has already been subject to quite a lot of feedback and discussion. Therefore, it is disappointing that we have found ourselves in these circumstances in which we have been given such a constricted time frame in which to debate what is quite an important bill, and that has not enabled those of us who have a responsibility to ensure that the legislation that we pass is sound to undertake the level of detailed scrutiny that we would ordinarily apply. Of course, along with everybody else, I only received draft 14 of the bill on Monday this week, noting that we are many drafts down the track, and was offered a briefing less than two hours later. I did not have a chance to open the email to look at the bill before I received that briefing because I do not spend my days sitting around waiting to receive stuff. I was already frantically trying to address a range of other commitments in that time frame. I am disappointed that I was not able to give such important legislation the level of detailed attention that I would ordinarily give it before a briefing. Nevertheless, I note that there has been considerable effort to respond to the many questions that have arisen as a result. I hope that we can find some comfort in what is incorporated in the bill.

Effectively, the bill addresses an identified issue in the Guardianship and Administration Act 1990 to ensure that people who are legally incapacitated and, therefore, unable to consent to medical research, can potentially

participate in medical research under certain circumstances. As has already been articulated, that raises a lot of serious ethical questions, and it is beholden on us to make sure that we develop a sound framework to address those concerns. As has already been said, this bill does not simply deal with the immediate emergency of COVID-19. The bill is of a general and enduring application, so it is neither just COVID-19 related nor for just 12 months like some of the other urgent COVID-19-related legislation that we have debated this week. Of course, it is applicable to the COVID-19 situation but, essentially, as I said, it implements recommendations that arose from a 2015 statutory review, so it has been around for a while.

That review was conducted by the Department of the Attorney General under the former government. The report lists a lot of consultation that occurred at that time, but, being a statutory review, the report covers a lot of ground. Specific reference is made to consent to medical research, and it goes into quite a bit of detail about how a potential future amendment should operate. This bill will apply when a person is incapable of making reasonable judgements about participating in medical research. That, of course, can occur for a number of reasons. The incapacity might be permanent, such as people who have longstanding brain injuries or cognitive impairment, or it might be temporary, such as someone who is heavily sedated, unconscious, or in a coma. Currently at law, no-one else can make that decision for them. That means that they simply cannot participate in medical research, and that is final—that is the end of it. As an advocate for people who have mental impairments, consumer organisations that I have had a lot of dealings with have raised concerns with me about the capacity of adult loved ones to avail themselves of potential treatments if they require them. This is a longstanding concern, particularly for parents of adult children with disability. They feel as though, when they deal with the health system, their children never receive the same level of care that other people get. From the conversations that I have had very briefly over the course of the last 24 hours, I know that there are people who are advocating very strongly to ensure that no-one is denied the best opportunity to get well in a range of circumstances simply because they have a permanent disability.

The concern now is that COVID-19 is a new disease; therefore, there is no existing standard treatment for it. Even though the issue has been around for a while, it has come to our attention as something that needs to be addressed now. The government has provided a number of examples in which the lack of an alternative consent process has been a problem in the past. The sorts of things that were raised with me were issues around cardiac arrest, with the typical outcome being death when the heartbeat stops, and the possibility of using experimental treatments. Other issues were illicit drug use, major trauma and sudden septic shock. Of course, there is the longstanding problem of dementia and the capacity to consent to treatment. Dementia is an interesting issue. I have always been concerned that people are quite happy to let people with dementia just slip away through lack of treatment. I remain really concerned about that from another side. I am certainly very interested in ways that those who have dementia can get the best possible treatment that might be available to them.

The bill defines medical research broadly. The explanatory memorandum states that it is modelled on the Victorian legislation and that medical research means research conducted with or about individuals, or their data or tissue, in the field of medicine or health. It includes, but is not limited to, pharmaceuticals or placebos. I want to make a comment about the placebo issue, because I note that the original 2015 report stated that the use of placebos is not in the best interests of an unconscious patient. It clearly has no benefit, so I am curious to know why that would potentially be in there. I will follow that up, unless the minister can answer that in the course of the second reading reply. Medical research also includes equipment or devices; health care; comparisons between health care; sample taking; observation and visual examinations; measurements and surveys; collecting, using and disclosing information; and anything else that is prescribed by regulation. We still do not really know the full extent of what will ultimately be determined to be medical research. It does not include analysing data about individuals or publishing personal information. Regulations can also prescribe what is not medical research. That will be interesting to see.

In the briefing, the briefers were at pains to explain that there is a continuum between research and standard treatment. The bill currently bans two types of medical research, with a maximum penalty of two years' imprisonment or a fine of $10 000. One of those is sterilisation—except as incidental to a different procedure—which is already currently banned. The other is electroconvulsive therapy. I note that that is a new ban under the bill, which is good, because ECT is very clearly monitored and prescribed, as is appropriate, by the Mental Health Act. It is a controversial treatment and we already have an act that completely governs how it can be utilised.

The bill sets out two processes that will permit medical research to proceed with a person who lacks capacity to decide for themselves. For the purpose of this debate I am going to use the term "patients" rather than "research candidates", as the bill refers to them. I do not think that is very helpful. If anything, it will raise hackles about what the bill actually is. If someone is a patient, that is much clearer than if someone is simply a research candidate. One process is a consent process in which consent is given by another person on behalf of the patient. That is a process that I feel very comfortable with, and others in this chamber have indicated they feel quite comfortable with it. I will go into that a bit more in a moment. The second process is the controversial one, which has raised people's concerns.

That is the non-consent process, in which the patient requires urgent treatment to save their life, prevent serious damage to health, or prevent them from suffering or continuing to suffer significant pain or distress. However, I note that excludes psychiatric treatment.

The consent process involves someone else making a decision on the patient's behalf. That person is called the research decision-maker. Appropriately, the bill lists a hierarchy of research decision-makers. The obvious first one is the person's enduring guardian, assuming they have one, who is reasonably available and authorised and willing to make that decision. If they are not available, the second person in the hierarchy is the patient's guardian, if they have one. Again, they have to be reasonably available and authorised and willing to make that decision. If there are neither of those, the next in the hierarchy is a series of other adults, who must be reasonably available, have full legal capacity, and be willing to make that decision. That list starts with the patient's partner or spouse, provided that they live with the patient or have a close personal relationship with them, as defined. Next is the patient's adult child. Otherwise, it reverts to the patient's parent or adult sibling, providing that they have a close personal relationship, as defined. That is when it starts to get a bit tricky, because one person's idea of a close relationship may not be somebody else's. Failing all of those, the next in the hierarchy is the patient's adult primary carer. That is provided that the person is not, effectively, employed or paid as that carer unless they are receiving a carer's allowance or a similar benefit. Failing that, the final person in the hierarchy is any adult who has a close personal relationship with the patient, as defined. I note that some members who have contributed have indicated concern particularly with this latter one. I do not share those concerns and I will explain why. Firstly, they are the last in a hierarchy of a range of people who will potentially be able to make decisions on behalf of an unconscious patient. I also know from my background in working with people who have severe and enduring mental illness that a lot of those people, unfortunately, tend to be estranged from their families and often do not have close partners who would be able to step into those roles. Very often, they rely heavily on close friends, who effectively become the family for those purposes. I note that under provisions in the Mental Health Act, we can acknowledge people who play those particular roles in people's lives. It still has to be demonstrated; someone cannot just turn up and say, "Hey, I'm Facebook friends with this person, so I get to make decisions about their treatment." It recognises that some people do not have those ready relationships. It is about ensuring that at least somebody who is close to the person and is trusted within their life is in a position to consent to treatment or, alternatively, is in a position to say no to treatment. That is the other part of it that we are recognising. Bearing in mind the hierarchy, at any given point someone can say, no, they do not consent to treatment being pursued.

It is important that when there are two or more people at the same level in the hierarchy, the decision needs to be made jointly, failing which, the responsibility for making a decision will flow to the next person in the hierarchy. That is good. I had a conversation with someone during the lunchbreak about whether their parents would ever agree on something, and they agreed that they would not, so that responsibility would flow on to the next person. It is important that we do not allow those impasses to prevent a decision from being made. The bill provides that medical research must not proceed unless and until someone in that hierarchy is found who, at the end of the day, is willing to make a decision and whose decision is to consent to, not refuse, the research proceeding. That person's ability to consent is fettered. They cannot consent to any medical research that has not been approved by a human research ethics committee established in accordance with the national statement. They must not consent unless an independent medical practitioner, as defined, has assessed, in the manner set out in the bill, the following things and has provided them with that assessment and the reasons for it in writing, if practicable, before the medical research commences: the patient is unlikely to become able to make their own decision within the time frame of that research and the patient's participation in the medical research is in their best interests, or at least is not adverse to their interests, and an example would be placebos. This assessment must take into account the patient's wishes, so far as they are ascertainable, as the paramount consideration. Other matters that must also be taken into account are the likely consequences for the patient of participating or not participating, any alternative treatments available, and any other prescribed matters. I will be curious to know what some of those prescribed matters would be.

There must be a comparison of the risks to the patient from the medical research or standard treatment, or from doing nothing if there is no standard treatment available. They cannot consent unless they personally decide, having regard to the assessment of the independent medical practitioner, that the medical research is ultimately in the patient's best interests or at least is not adverse to their interests, and either the research is non-invasive to the patient or, if it is invasive, the research has no known substantial risk to the patient; or, if it does and an existing treatment is available, those risks are not greater than those of the existing treatment; or, if they are and there is no available existing treatment, those risks are not greater than those of not doing the research. They must not consent if this would be inconsistent with the patient's current advance health directive. I ask the minister to please confirm that this process will prevent the trumping of the patient's wishes, as long as they are known, because of the two safeguards—that is, the advance health directives and the paramountcy of the patient's wishes and the best interests assessment made by the independent medical practitioner. It will prevent the trumping of the research decision-maker's decision by a researcher or a medical practitioner because the final responsibility for making the decision lies with

the research decision-maker, not with the researcher or a medical practitioner. It will prevent consent being given by a research decision-maker who does not have the patient's best interests at heart. Some of the examples that were raised in previous contributions talked about issues of family violence, as well as elder abuse—for example, hoping for an inheritance if the patient dies. This is something that was mentioned by the committee that looked into the prevalence of elder abuse. It found that it was a huge issue within the community, and consent can be given only if it is in accordance with the three assessments by the independent medical practitioner, including the assessment that the consent is in the patient's best interests.

I feel quite comfortable with that consent process. I feel as though there are a lot of safeguards in there. Putting it very simply, I like the fact that these changes will allow my husband to make decisions in my best interests—because I feel confident he would—on not only conventional treatment, but also experimental treatment, if he is put in the situation of trying to make sure that I am kept alive and that I am going to be okay. Therefore, I recognise that that process will potentially enable a great number of people to receive treatment, who would otherwise have the treatment denied to them because it cannot be agreed to by anyone, and that will be at the behest of the people who love them.

I will now go to the second process, the non-consent process in the bill. This is the one that has created so much concern and the one that a lot of people are talking about wanting to have further examination of, to look at some sort of sunset clause provision. This bill is being expedited in a way that a bill of this substance would ordinarily not be. The non-consent process in the bill will apply only to urgent situations, but under that process, the medical research must not proceed unless a number of factors apply. The research will need to have been approved, like in the previous process, by a human research ethics committee that is established in accordance with the national statement. The patient must need urgent medical treatment, meaning, as I said earlier, to save their life or to prevent serious damage to their health or to prevent them suffering or continuing to suffer significant pain or distress, but, again, not including psychiatric treatment, sterilisation or electroconvulsive therapy. Another factor will be that the patient cannot make a reasonable judgement for themselves about whether to participate, and no pre-existing research decision has been made by the other consent process. Another factor will be that it is not practicable for the researcher to use the consent process and it is unlikely to be practicable to get consent via that process in the time frame for the research to happen. Other factors will be that insofar as the researcher is aware, or ought to reasonably be aware, there is no inconsistent advance health directive of the patient against the research proceeding, and an independent medical practitioner has made the same three assessments as I mentioned earlier.

But I ask the minister to confirm that this process will prevent the researcher from, again, trumping the independent medical practitioner's assessment, because the research cannot proceed, except in accordance with the assessment of the independent medical practitioner. If all the conditions that I have just said are met and the medical research proceeds, the lead researcher will still be obliged under the bill to continue taking reasonable steps to locate and obtain the consent of a research decision-maker using the consent process that I described a few moments ago. In this way, I recognise that the urgent non-consent process is potentially an interim process, because they may not end up finding a research decision-maker. I understand that it is intended to last only until that other consent process can be used. I ask the Leader of the House to confirm whether that is the case.

When and if the patient regains the ability to decide for themselves or a research decision-maker is located and they decide to refuse consent, the lead researcher must discontinue the research as soon as it is safe to do so and must not recommence it unless they are able to obtain consent. What happens if the proper process in the bill is not followed? What are the consequences for researchers who do not comply with the process in the bill? Will they lose the protections in the bill that take them to have made valid decisions and to have acted as though the patient had full legal capacity and had consented to the medical research? There are not any penalties in the bill, or the act, except for a breach of the bans on sterilisation and electroconvulsive therapy. The consequence of noncompliance is the risk of professional disciplinary proceedings arising from a formal complaint against the researcher.

Proposed section 110ZZ will permit a person who is interested in the decision to apply to the State Administrative Tribunal for a review. This provides a review process, for example, to a person who has a close relationship with a patient and cares about their wellbeing but who is not the person that the hierarchy in the bill designates to be the research decision-maker.

As always, I am delighted to see a review clause. I am pleased that the review period is one year. This is appropriate, considering the very grave and complex nature of this bill, and also the truncated time for parliamentary scrutiny of it. I thank the Attorney General for bringing that review period forward. I also want to thank the Minister for Health for his written undertaking to the Greens, the Liberals and the Nationals—that I know of—to refer the legislation for review to the Education and Health Standing Committee of the Legislative Assembly following its passage. Ideally, of course, as has been said, parliamentary committees review legislation before it is passed, not after—that is the normal way we do things. I acknowledge that we are living in extraordinary times during this pandemic. I at least appreciate that the minister has agreed to refer it to that Legislative Assembly committee. I also

indicate that I will be supporting its referral to the Legislative Council Standing Committee on Legislation. I think that is a very wise and necessary move considering the seriousness of this legislation and the truncated time in which we have had the opportunity to appropriately assess it.

I understand we may be considering a sunset clause of sorts in relation to proposed section 110SZ, which relates to urgent medical research without consent. That should receive serious consideration and potentially support. I want to see the wording of the final amendment. I think that is the bit that probably creates the most disquiet for people. Otherwise, in relation to the other provisions that enable people that I know who love me to be able to make a whole range of decisions on my behalf, and for other people to have decisions made on their behalf that will potentially have the capacity to save their lives or prevent them from unnecessary further harm, they are sound and quite consistent with the intent and the purpose of the Guardianship and Administration Act as a whole. I am disappointed that it took this crisis for this legislation to come on when it did. I would have preferred this to have been brought on much earlier. I am also aware that we have been waiting quite some time for a lot of other reform of the guardianship act.

With those words, I look forward to hearing the Leader of the House's response and will have further questions when we go into Committee of the Whole.

HON SUE ELLERY (South Metropolitan — Leader of the House) [2.34 pm] — in reply: I thank members for their contributions to the debate on the Guardianship and Administration Amendment (Medical Research) Bill 2020. I want to frame my second reading reply in a slightly different way than I might otherwise, because extensive discussions have taken place behind the Chair. In particular, I want to thank Hon Michael Mischin for his constructive contribution on how we might take this forward, and recognise concerns that have been raised by honourable members. I indicate that we have before us supplementary notice paper 176, issue 1, for those who have not seen it yet. There are amendments in the name of Hon Michael Mischin on the supplementary notice paper, and the government is supportive of those. As I speak, parliamentary counsel is looking at whether we need some transitional provisions. I do not have anything in front of me now but there might be the need for those provisions, and we will deal with them in Committee of the Whole if needed.

Hon Michael Mischin: I would be inclined to recommend to the opposition that if something like that were found to be necessary, on mature reflection, we would support that, given that the imperative is to provide the assistance that patients may need today.

Hon SUE ELLERY: I thank the member. I appreciate that.

The other thing that is not before us right now but which has been referred to—I want to give members an understanding of the government's position on that—is the motion to refer the legislation, once passed, to the Standing Committee on Legislation. The government will also support that referral. I thank members for their flexibility and cooperation in what have certainly been trying times in getting to this point. I know that members have made themselves available for multiple briefings and I know that they have been in close contact with the advisers. I also want to thank the advisers.

The amendments on the supplementary notice paper effectively form a sunset clause. I want to put some comments on the record about that. It is not the government's preferred position. It is certainly not the preferred position of the medical research community and I want to not only explain why, but also indicate nevertheless that the government will be supportive of those measures. We do not hold the view that a sunset clause is ideal. We have some concerns about the consequences. As I said, nevertheless, we will support it. The concern has been that a sunset clause would present a significant practical difficulty for the provision of medical research treatment. There is a risk that the effect of such a limitation would mean that clinical medical research would be lost to Western Australia. It is already very difficult to secure medical research projects and grants here in Western Australia. It may not be well known, but fewer than 10 per cent of applications for research grants nationwide are successful; hence, there is a huge degree of competition. It should also be appreciated that a typical research project has a life span of three to five years. That involves hiring staff, making sure the facilities are available and many other logistical matters. That is for a single research project. The difficulties are multiplied for a multicentre research project. As well as that, if there is a cluster of research projects, a centre of excellence may need to be established. The percentage of successful grants for Western Australia is already less than the national average.

If there is any question about whether research commenced in Western Australia may continue after a sunset clause, or that research must cease, it is easy to imagine that research projects and research grants will simply not be allocated to Western Australia. Any ambiguity about the ability to carry out research will militate against the very able medical practitioners in this jurisdiction who strive to attract research to this state. Further, it will be challenging to get ethics approval for a clinical trial if the legal framework to enable the trial is not guaranteed for its full length. A specific example of research in WA that cannot be addressed in full due to the lack of this legislation is the "critical illness in shock" study, which focuses on patients being admitted to hospital with a possible

COVID-19 infection. The submission was reviewed and supported by the human research ethics committee but was unable to proceed for patients who were not able to consent. This was an observational study of suspected or confirmed cases of COVID-19 infection presenting to the emergency department with respiratory distress and/or hypoxemia. This study would address the urgent worldwide need to develop therapeutic targets aimed at reducing mortality associated with COVID-19, and, in particular, to understand the differential death rates in different age groups that cannot be explained by comorbidity alone. If it could proceed, this study would place WA researchers at the centre of the global fight against this infection. I will table a letter from the Royal Perth Hospital Human Research Ethics Committee.

[See paper 3768.]

Hon SUE ELLERY: The HREC noted that there is not currently a mechanism in WA law to authorise the enrolment of patients incapable of prospective consent to the cis-COVID cohort. As such, the HREC resolved to approve the project for enrolment of those patients who can provide prospective verbal consent, which is enrolment pathway 1, and not approve enrolment pathways 2 to 4. The HREC will expedite re-review of the amendment to consider approval of enrolment pathways 2 to 4 should a legal mechanism become available.

I am not referring to just some abstract difficulty. Ultimately, when medical research is not carried on in this jurisdiction the losers are those who populate the hospitals who might benefit from the treatment that is provided as part of the medical research—that is, citizens of WA will miss out. It is well established that hospitals that are active in medical research provide better overall outcomes for their patients compared with hospitals that do not carry out medical research. Medical research is in the public interest. Nevertheless, the government will support, as I indicated, the amendment, recognising the very tight time frames that we have all been working with and appreciating the input to come from the Standing Committee on Legislation.

I now turn to each of the specific comments that have been made, bearing in mind that every member who has contributed has referred to a sunset clause and I have addressed that issue already. Hon Aaron Stonehouse outlined his concerns about the categories of research decision-makers—that is, substitute decision-makers—who could be called to make a research decision for someone who lacked capacity to make a decision themselves and that that could go as far as including good friends. The inclusion of persons who demonstrate a close and personal relationship outside of family members is not new. Proposed sections 110ZP and 110ZQ, which provide who may be a substitute decision-maker for a research candidate, are modelled exactly on existing section 110ZJ under part 9D of the Guardianship and Administration Act pertaining to treatment decisions. It is not unusual that another non-family member who maintains a close personal relationship with the candidate would take the role of a research decision-maker if required and in the absence of a spouse, nearest relative or unpaid carer.

The member also made the point that what is introduced should become a separate piece of legislation limited to COVID-19 because it will apply to many other forms of medical research. The honourable member may not be aware of the practical difficulties associated with attempting to limit the operation of proposed section 110ZS to the coronavirus pandemic. The practical difficulty is that when a patient appears in an emergency department, it is not always possible to tell what they are suffering from precisely. The present pandemic illustrates this point well. Typically, the symptoms of COVID-19 are respiratory systems; however, that is not always the case. There is a subset of cases in which patients do not have any respiratory symptoms but manifest the symptoms of a person having a heart attack. It would be desirable to provide urgent medical research treatment to a person who comes in with the symptoms of a heart attack, but that can only happen if those symptoms have been caused by an underlying condition, which is COVID-19. It will never be possible for a medical researcher to provide urgent medical research treatment to a person manifesting heart attack symptoms, because they will never be able to test whether the patient has COVID-19 within a time frame that makes the urgent medical treatment relevant. The same point applies equally when a patient goes into an emergency department with comorbidities and one of those comorbidities is that the patient has COVID-19. It follows that limiting the bill's operation to only the coronavirus pandemic renders the operation of this provision entirely impractical. As a matter of principle, it is also wrong to limit the operation of the bill to only the coronavirus pandemic. There have been demonstrated benefits of doctors making research decisions on behalf of incapacitated persons in other areas. For example, the NICE-SUGAR trial of insulin to maintain tight blood sugar control, a widely accepted practice, found that this approach killed three extra patients per 100 treated. Entry criteria required a blood sugar level of more than 10 and unconscious patients needed to start the trial immediately, not in a few hours. Increased blood sugar levels happen any time of the day or night. It was impractical to get prospective agreement once it happened. The NICE-SUGAR trial evaluated a widely accepted practice but found that this practice killed three extra patients per 100 treated.

Hon Nick Goiran spoke in his contribution about the process and the time lines that have brought us here. I am not going to go into that other than to make the point that the amendments in the bill will ensure that all Western Australians will have the opportunity to participate in world-leading medical research specifically targeted at combating COVID-19. The member indicated that he felt there was—I am paraphrasing—some

confusion about the prevailing arguments in Parliament over the past year or so when we were dealing with the Voluntary Assisted Dying Bill 2019, for example, about promoting the autonomy of individuals, and he questioned where that argument sat. The principles in that argument sit with the principles that are proposed here. The government acknowledges that this bill presents a conflict between two different fundamental rights: the right to life when being administered life-saving treatment and the right not to be subjected to medical experimentation or treatment without consent. The government is satisfied that the bill strikes the appropriate balance between those important rights. That might be a matter that goes to our individual consciences.

Consistent with the common law, a person's own refusal of particular medical treatment has overriding weight. For the critically unwell, being able to administer non-standard treatments under law that authorises them to do so in urgent situations is aimed at attempting to save their lives and, in doing so, restore their personal autonomy to allow those persons to get back to their family and independent lives. Urgent medical research without consent can be carried out only under limited circumstances and provided that a number of safeguards are assured. The specific circumstances that must occur in order for urgent medical research to be considered without consent are that the research candidate requires urgent care; the research candidate is unable to make reasonable judgements about their participation in the medical research; there is no research decision in relation to the candidate in their participation in the research; it is not practicable for the researcher who proposes to conduct the research to obtain a research decision in relation to the candidate from the research decision-maker for the candidate; it is unlikely that it will be practicable for the researcher to obtain such a decision within the time frame approved by the human research ethics committee.

The safeguards that must be complied with for urgent medical research to be conducted are that the medical research has been approved by the HREC; the HREC approved the medical research without the requirement for prior consent to participate in the medical research; the researcher receives an independent medical practitioner's determination in accordance with proposed section 110ZV; that the candidate is not likely to be able to make reasonable judgements about participation in the research within the time frame for the research as set out by the HREC; the researcher receives an independent medical practitioner's determination that the candidate's participation is in the best interests of the candidate or is not averse to the interests of the candidate; the researcher receives an independent medical practitioner's determination that the candidate's participation will involve only observing the candidate or carrying out non-invasive examination treatment or procedure, or will not involve any known substantial risks to the candidate; or, when there is an existing treatment, the medical research will not involve any known substantial risks to the candidate greater than the risks associated with the treatment; or will not involve substantial risks to the candidate greater than if the candidate did not participate in the research.

The honourable member referred to the recommendations of the statutory review of the Guardianship and Administration Act in 2015. The government is committed to implementing all the supported recommendations from that statutory review. However, in the current environment, the recommendations that address the issue of consent to medical research are crucial. The amendments in the Guardianship and Administration Amendment (Medical Research) Bill 2020 will ensure that Western Australians have the opportunity to participate in world-leading medical research specifically targeted at combating COVID-19. The drafting of a broader amendment bill will progress as soon as the legislative priorities occur.

The honourable member then referred to the position of the Public Advocate. He said that the Public Advocate said during the 2015 statutory review that research should be carried out only when there is a direct benefit to the person, and that placebos would not be of benefit to a person. I have a letter of support from the Public Advocate that I will table in a minute. It states —

> I met with Professor Gary Geelhoed, Executive Director, Western Australian Health Translation Network, on 18 June 2018 who addressed the concerns I raised in the Statutory Review regarding the provision of placebos in medical research. I was assured that, should a person receive a placebo during medical research, they would still receive the best possible existing treatment for their condition, they would just not receive the novel treatment being trialled in the research. I understand placebos to be an important part of medical research, and am confident that, should a person receive a placebo during medical research, they will still be receiving the best available treatment for their condition.
>
> I am supportive of the amendments in the Bill which will enable myself, as the Public Advocate, to consent to medical research on behalf of a represented person, where that research is in the person's best interests and will have no detrimental impact on the person. I note that the assessment by an independent medical practitioner of the research candidate's best interests provides a key safeguard which assist guardians and other research decision-makers in making their decision about the participation of a represented person in medical research.
>
> I have viewed all drafts of the Bill as it has developed, and am confident that the Bill ensures that the best interests of the person remain central in the amendments. As is required in the *Guardianship and*

> *Administration Act 1990*, the amendments ensure that all medical research decisions are made in the best interests of the person, and regard the wishes of the person as the paramount consideration.

I table that document.

[See paper 3769.]

Hon Michael Mischin: Can you tell us the date of that letter?

Hon SUE ELLERY: Yes, I did. It was dated 2018—hang on; I will check it for the member. The Public Advocate said in her letter that she met with Professor Gary Geelhoed on 18 June 2018 and her letter is dated 1 April 2020.

Hon Michael Mischin: That was yesterday, right?

Hon SUE ELLERY: Correct. Hon Charles Smith said that this legislation proposes to treat people without capacity like guinea pigs to be experimented on, and that it was unreasonable to let these important decisions fall upon guardians. Although the language is colourful, we need to address the essential core of his argument and reject it. The bill clearly puts the ethical treatment of patients at the forefront in any decision about whether they are included in medical research. Before consideration can even be given to include a patient in medical research, the research must be approved by a human research ethics committee. Further protections in the bill require that an independent medical practitioner must determine that it is in the best interests of the patient, having regard to their wishes as a paramount consideration. The bill will allow patients to access new treatments that would be available only through clinical trials, which can provide benefits to the patient as well as generate knowledge of benefit to the wider community.

I thank Hon Colin Holt for his contribution as well. He made the point that there are sound reasons that we should not limit the operation of this legislation to the COVID-19 crisis. I shared those with the house in my response to comments by Hon Aaron Stonehouse.

Hon Alison Xamon asked for confirmation of a number of things and raised some questions, such as how the use of a placebo can be of any benefit for persons who are not aware of the effect. The use of placebos on unconscious patients is still effective in research because it ensures that the results are not affected by the clinician's behaviour and expectations, which could compromise the research outcome results. To exclude the use of placebos would go against fundamental standards of research methodology, which also includes randomisation and blinding, as discussed earlier, and would make it impossible to enrol patients in clinical trials of COVID-19 drug treatments and vaccines. Clinical trials are probably the only opportunity to access those treatments in the short to medium term. The honourable member wanted to be assured that the researcher would not be able to trump the decision of a research decision-maker or an independent medical practitioner. Under the proposed legislation, it will be impossible for a researcher to make any decision that is inconsistent with a decision made by a research decision-maker or independent medical practitioner. In fact, a researcher will not make any research decisions under this legislation. A researcher must get the approval to conduct medical research from either a research decision-maker, a substitute decision-maker, or, in the case of an urgent research decision, an independent medical practitioner.

At the beginning of my comments, I referred to parliamentary counsel working on whether we need transitional provisions. I now have that information and it proposes certain amendments in my name. I will sign those and ensure that they will be added to a supplementary notice paper. While the supplementary notice paper is being prepared, I have copies that might help members. That concludes my comments. I want to again stress my appreciation to members of the house, particularly Hon Michael Mischin, for their constructive approach. If there is something I have not covered, and no doubt some members will want to ask questions about specific elements of the bill, we can do that in the Committee of the Whole House stage.

I commend the bill to the house.

Division

Question put and a division taken with the following result —

Ayes (23)

Hon Ken Baston	Hon Colin de Grussa	Hon Colin Holt	Hon Dr Sally Talbot
Hon Jacqui Boydell	Hon Sue Ellery	Hon Kyle McGinn	Hon Dr Steve Thomas
Hon Tim Clifford	Hon Diane Evers	Hon Michael Mischin	Hon Darren West
Hon Alanna Clohesy	Hon Donna Faragher	Hon Simon O'Brien	Hon Alison Xamon
Hon Peter Collier	Hon Adele Farina	Hon Martin Pritchard	Hon Pierre Yang *(Teller)*
Hon Stephen Dawson	Hon Nick Goiran	Hon Samantha Rowe	

Noes (4)			
Hon Rick Mazza	Hon Robin Scott	Hon Aaron Stonehouse	Hon Charles Smith *(Teller)*

Pair	
Hon Tjorn Sibma	Hon Colin Tincknell

Question thus passed.

Bill read a second time.

Committee

The Chair of Committees (Hon Simon O'Brien) in the chair; Hon Sue Ellery (Leader of the House) in charge of the bill.

Clause 1: Short title —

Hon NICK GOIRAN: The government advised the Select Committee into Elder Abuse by letter, dated 26 April 2018, that it supported 77 out of the 86 recommendations from the 2015 statutory review and that a bill would be introduced in the spring of 2018. Which of those 77 supported recommendations are being implemented by this bill?

Hon SUE ELLERY: I am not able to give the member a list of those now. I am happy to give him an undertaking that I will get an analysis done and provide that to him at a later date. I do not have that information here.

Hon NICK GOIRAN: I am happy to be corrected if I am wrong, but I understood that the government had made some reference to the statutory review and the recommendations, in either the second reading speech or the explanatory memorandum. If that is the case, it is reasonable to assume that the government would know which of the recommendations it is currently implementing. I note that the government devoted an entire paragraph in the second reading speech to this statement. It states —

> The statutory review was tabled by the Liberal–National government in 2015, but no action was taken to implement the recommended legislative amendments to the Guardianship and Administration Act 1990. Although the McGowan government recognises …

There was enough time in the second reading speech to put together the political commentary, but when it comes to the recommendations that the government says it is implementing by virtue of this bill, we cannot be told which of the 77 they are. I am surprised that it is impossible for anyone to identify even one recommendation that was made in the 2015 statutory review that is being implemented at this time. The context of that is, as I said in the second reading debate, the Attorney General went to great pains to tell the Select Committee into Elder Abuse how many recommendations the government was supporting and that a bill would be introduced in spring 2018. He went on to say that the bill had been approved by cabinet in 2017. I underscore that over the past two years I have repeatedly raised this issue. I find it astonishing that we could now have a bill that has been declared urgent and we cannot identify any recommendations at all arising out of the statutory review.

Hon SUE ELLERY: The advice I have is that there are two recommendations—6.1 and 7.

Hon NICK GOIRAN: Was anything in this bill before us at the moment expressly recommended not to be done in the statutory review?

The CHAIR: If the minister wants to respond, I might have some advice. Minister, I give you the call.

Hon SUE ELLERY: We are not in a position where I have the capacity to do an analysis between what is before us now and what appeared in the statutory review recommendations. I have already given an undertaking for the first question; I will give it again. I give an undertaking that I can find that information, but I do not have it available here. Although I am sure it is of interest, nothing in the bill turns on it.

Hon NICK GOIRAN: That is most certainly not correct; it absolutely turns on it. If there is something in the statutory review from 2015 that says "Do not do X", and this bill is doing X, I want to know about that so that I can vote against that clause. The government has had since 2017 when cabinet approved the bill to get its head around these particular things. We have had less than 24 hours. That is the context. It is pointless saying that it does not turn on it; it very much turns on it. I draw to the minister's attention the remarks that she made in her second reading speech, which repeatedly refer to the recommendations in the statutory review but does not tell us which recommendations they are. On a different date, the minister appreciates that I would be pursuing this further. Regrettably, we are operating under the temporary order on which I made remarks earlier.

Would the minister be in a position to assist the chamber by identifying in which clause the clerical error was found that gave rise to this bill being labelled "176–1B"?

Hon SUE ELLERY: I will try. I do not have that information available to me at the table. There are people who are listening to the debate who might be able to send a note in, if they could tell us, but I do not have that available to me at the table and I do not want to hold up consideration of the bill to wait for that information. But I will give an undertaking that if it comes in, I will provide it.

Hon MICHAEL MISCHIN: I have one question on clause 1. It flows from the blurring, I suppose, of the boundaries between research and treatment, and whether in the circumstances the government had given consideration to a standalone and discrete medical research bill that covers the sort of stuff that we are dealing with today, rather than grafting it onto amendments to the Guardianship and Administration Act and causing some of the confusion that has arisen over the last several days.

The CHAIR: If the minister wishes to respond, I shall give her the call, but I remind members that this debate is on clause 1 of the bill. Perhaps some of the observations that are being made and the questions raised relate to another stage. Nonetheless, if the minister wishes to cooperate, given the extraordinary circumstances we have, I will give her the call.

Hon SUE ELLERY: Although the government is keen to support medical research, no consideration was given, on the best advice available to me now, to doing it by way of a separate bill.

Hon RICK MAZZA: This bill was introduced into the Council as an emergency COVID-19 bill, among a suite of emergency bills. Besides COVID-19, under what other conditions is it envisaged or planned that experimental research might be carried out on patients without their consent?

Hon SUE ELLERY: It is not possible to give the member a list. It is designed for anybody who is critically ill or injured, and that could be of any nature. I gave some examples in my second reading reply, but there is not a defined list and there could not be a defined list. It could include any condition that confronts medical practitioners when someone is in a critical condition, and that is across the broadest possible spectrum.

Hon RICK MAZZA: Can I take it from that answer that this bill is not specifically for the COVID-19 emergency? It is, in fact, for experimental research on people without their consent for any condition?

Hon SUE ELLERY: I think the honourable member has missed the point that I tried to make in my second reading speech and in my second reading reply. The circumstances that we face now are due to COVID-19. The member used the word "experimental", but there are medical research activities directly related to COVID-19 that could be used to save people's lives now and to save Western Australian lives and other lives in the future. The urgency is because of COVID-19, but the member was right when he made the point that the scope of the bill is not limited to COVID-19. What makes it urgent is that we are confronting COVID-19 right now.

Clause put and passed.

Clause 2: Commencement —

Hon MICHAEL MISCHIN: The Leader of the House has foreshadowed a couple of amendments, but I will deal with my amendment and we will see how the process goes from there. The purpose of my amendment 1/2 on issue 1 of supplementary notice paper 176 is to delete the lines regarding the operation of the act to enable sections 1 and 2 to commence on the day on which the act receives royal assent, and the rest of the act on the day after the date of assent, and to introduce a provision that will provide that new section 12A of the bill will come into operation four years—it is framed as 48 months—after the day of assent. Proposed section 12A appears as new clause 12A in the bill, which I propose to move at amendment 2/NC12A. It inserts on page 31, after line 25, a new clause, which will become a section, deleting proposed section 110ZS of the legislation following the passage of this bill. In a nutshell, when the bill comes into operation as an act, it will operate into perpetuity, but four years after the commencement of the operation of the act, new clause 12A will come into effect and kill off proposed section 110ZS; hence, it will operate as a sunset clause or termination of that key and controversial section of the proposed act.

If possible, I think it is sensible that both those amendments be moved as a group to delete the relevant lines and to insert certain passages. Obviously, one is worthless without the other. I note that the Leader of the House has foreshadowed a couple of tweaks to what I had proposed. One is to change the reference to "48 months" to "four years". I am happy with that, if there is a way of conveniently amending my proposed amendment to use current parliamentary drafting practice. Otherwise, she intends to insert a reference, along with new clause 12A, to section 14. That section 14 will be embodied in a new clause 14, which she has foreshadowed is a set of transitional provisions that will appear as a schedule to the substantive act. I have a few questions about those transitional provisions—how they will operate, and their metes and bounds—so I do not want to agree to the insertion of a reference to section 14 yet. Perhaps we can recommit the clause in due course, or something to that effect. At this stage, I might move an amendment to my proposed amendment to delete "48 months" and replace it with "four years". If that amendment is allowed, I will move the substantive amendment and also the reference to the amendment concerning new clause 12A. Is there a way that can be done conveniently?

Perhaps, Mr Chair, it will be convenient for you to leave the chair until we can sort this out in some sensible way. I am happy to accommodate that as well.

The CHAIR: We will deal with this very quickly, without me leaving the chair. Expeditiously is a good word.

Hon MICHAEL MISCHIN: I hope I am not confusing matters more, but if I move my amendment on the amendment to clause 2, when we get to the foreshadowed amendment, which is right at the end of the bill, and it is passed, we can perhaps recommit clause 2, as amended, and fix it.

The CHAIR: Firstly, member, I do not believe you have moved your proposed amendment to clause 2 yet, so we do not need to amend that. You can simply move the fresh version that you have foreshadowed. Just before you do that, I want to get one article of advice.

I now invite Hon Michael Mischin to move his amendment to clause 2.

Hon MICHAEL MISCHIN: I propose to do these as a job lot because they are related to each other and are meaningless without the second amendment.

The CHAIR: No; we are dealing with clause 2 in the first instance.

Hon MICHAEL MISCHIN: Very well. I move, with one variation —

Page 2, lines 7 and 8 — To delete the lines and substitute —

receives the Royal Assent (assent day);

(b) section 12A — on the day after the period of 4 years beginning on the day after assent day;

(c) the rest of the Act — on the day after assent day.

The CHAIR: Hon Michael Mischin has moved the amendment with the modification, as he has just indicated. The question is that the words to be deleted be deleted.

Hon SUE ELLERY: I just indicate, as I have already, my support for the amendment moved by Hon Michael Mischin. We think it is important that we have some transitional provisions in place, so I have tabled those and we are waiting for them to appear on the supplementary notice paper. The amendment before us is supported by the government.

The CHAIR: Members, so that we do not chew up time and because there are some complexities here, I shall leave the chair until the ringing of the bells, but it will be brief.

Sitting suspended from 3.29 to 3.38 pm

The CHAIR: Members, we return to the Guardianship and Administration Amendment (Medical Research) Bill 2020. Members may have noticed that while I was out of the chair, the clock was stopped, so no time has been lost for consideration. We have moved to clause 2. The question is that clause 2 do stand as printed, to which Hon Michael Mischin has moved his amendment. I now give the call again to Hon Michael Mischin.

Hon MICHAEL MISCHIN: Thank you, Mr Chairman; it is comforting to know that in the last few minutes I have not aged at all because the clock was stopped!

To inform members of the current progress, as members are aware, an amendment is proposed to the commencement in respect of a sunset clause. The government also proposes a new clause 14, which is not on the current supplementary notice paper but will be, that will have some transitional provisions. In order to conveniently deal with all these things in a sensible sequence, it is proposed that I seek leave to withdraw my amendment to clause 2, which currently stands at serial 1/2 on issue 1 of the supplementary notice paper so that it can be dealt with at a later stage once the substantive amendments and transitional provisions are dealt with. Therefore, I seek leave to withdraw that amendment at this time.

Amendment, by leave, withdrawn.

Hon MICHAEL MISCHIN: Further to that, I will move that the consideration of clause 2, the commencement provision of the bill, be deferred until after consideration of the remainder of the bill and, in particular, after consideration of the foreshadowed new clause 14, which does not appear in the bill but which the government has indicated it will move to introduce.

Further consideration of the clause postponed, on motion by Hon Michael Mischin.

[Continued on page 2063.]

Clauses 3 and 4 put and passed.

Clause 5: Section 3AA inserted —

Hon NICK GOIRAN: Does clause 5 implement recommendation 7 of the statutory review other than to add the word "medical"?

Hon Sue Ellery: Yes.

Hon NICK GOIRAN: Recommendation 7 of the statutory review was that the definition of "research" be the same as the definition in the "National Statement on Ethical Conduct in Human Research" prepared by the National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors' Committee. Can the national statement on ethical conduct, which contains that definition, be tabled?

Hon SUE ELLERY: Yes. I table the "National Statement on Ethical Conduct in Human Research" from Universities Australia, the Australian government, the National Health and Medical Research Council and the Australian Research Council.

[See paper 3770.]

Hon NICK GOIRAN: Clause 5 sets out a very extensive new term of "medical research", which includes placebos. When we look at clause 5 in conjunction with other clauses, it will allow, at proposed section 3AA(2)(a), for the administration of placebos.

Hon Sue Ellery: Member, could you tell me which page that is?

Hon NICK GOIRAN: It is on page 4. Clause 5 inserts a new section 3AA. Specifically, proposed subsection (2)(a), when linked with other sections, will allow for the administration of pharmaceuticals and placebos. I am particularly interested in the issue of placebos at this point, as it was discussed by several members during the second reading debate. Would any compensation be available to a parent who consented to their child being administered a pharmaceutical only for a placebo to be administered to the child instead?

Hon SUE ELLERY: I am advised no, because the doctors and the nurses do not know whether they are applying pharmaceuticals or placebos.

Hon NICK GOIRAN: As I said, proposed section 3AA(2) sets out a large list of categories—things that will constitute medical research if this clause is approved. Which of those things listed in proposed section 3AA(2) can already be provided to a Western Australian with the consent of their substitute decision-maker?

Hon SUE ELLERY: None for treatment for the purposes of medical research, but any of them for the purposes of ordinary treatment.

Hon NICK GOIRAN: I take the Leader of the House to proposed subsection (2)(c), which states —

> providing health care that has not yet gained the support of a substantial number of practitioners in that field of health care;

Would it be possible for that health care to be provided to a Western Australian at the moment?

Hon Sue Ellery: Yes.

Hon NICK GOIRAN: If that is the case, that is the answer to the question.

I take the Leader of the House to proposed subsection (2)(l), which states —

> any other activity prescribed by the regulations to be medical research.

What is intended to be prescribed as "any other activity" under the regulations? While I am on my feet, I ask the Leader of the House to turn to page 6. The same issue arises at proposed subsection (3)(b), except the distinction between the two is that the first set of regulations will have things that can be considered to be medical research and the second set will indicate what things are not medical research.

Hon SUE ELLERY: Right now there is no intention to incorporate anything specific in the regulations that could be made under that head of power. The intention, though, is to see how the provisions work and whether anything needs to be added to it. But, right now, there is no intention for anything specific to be added to it.

Clause put and passed.

Clause 6 put and passed.

Clause 7: Section 45 amended —

Hon NICK GOIRAN: What are the circumstances in which a plenary guardian can consent to the sterilisation of a represented person under proposed section 45(4A)(b)?

Hon SUE ELLERY: Never for the purpose of medical research.

Hon NICK GOIRAN: Can a plenary guardian never consent to the sterilisation of a represented person, full stop, or is the minister caveating it by only for "medical research"?

Hon Sue Ellery: For the purpose of medical research.

Hon NICK GOIRAN: If it is not for the purpose of medical research, what are the circumstances in which the plenary guardian can consent to the sterilisation of represented persons who are contemplated in proposed section 45(4A)(b)?

Hon SUE ELLERY: That might be an interesting debate to have —

Hon Nick Goiran interjected.

Hon SUE ELLERY: Let me give the answer that I want to give. That may be an interesting debate to have, but the relevance of what is before us today is about the link to medical research. I provided an answer to the provisions of the bill before us in respect of medical research. The question the honourable member has asked, as I understand it, is about other existing provisions of the existing act, which is not what we are debating today.

Hon NICK GOIRAN: If we pass clause 7 in its current form, does it leave the door open for a plenary guardian to be able to consent to sterilisation of a represented person?

Hon SUE ELLERY: Again, not for the purpose of medical research. I take the member to page 20 of the bill, clause 12, proposed section 110ZT, "Particular medical research not permitted". It states —

> (1) In this section —
>
> ***procedure for the sterilisation*** has the meaning given in section 56.
>
> (2) A research decision-maker for a research candidate cannot consent under this Part to —
>
> (a) a procedure for the sterilisation of the candidate …

It then goes on to another form of treatment.

Hon NICK GOIRAN: What would be the impact of deleting line 27 on page 7?

The DEPUTY CHAIR: Member, can I confirm that we are talking about deleting "except in accordance with Division 3"?

Hon NICK GOIRAN: Yes.

Hon SUE ELLERY: I think that the honourable member is proposing doing something that is beyond the scope of the bill before us. The provisions in division 3 already exist. The bill before us now is about very specific provisions for medical research. At some point in the future, the honourable member might want to do something about the existing provisions in division 3, but they exist already and are not part of what is being considered in the bill before us now. The scope of his question is beyond what the bill in front of us is trying to do.

Hon NICK GOIRAN: Let us test that. Mr Chair, can I get your ruling on whether it is permissible for the chamber to delete line 27?

Hon Sue Ellery: The chamber can do whatever it wants.

The DEPUTY CHAIR (Hon Dr Steve Thomas): Yes, I was about to say that the chamber is capable of changing any piece of legislation it wishes. That is my ruling.

Hon NICK GOIRAN: Thank you, Mr Chair. Since we now know that it is within the scope and power of the chamber to delete line 27, what would be the impact on the bill if that were to occur?

Hon SUE ELLERY: The impact would be that existing provisions, which were not contemplated being changed as part of this bill, would no longer apply. The government is not prepared to entertain that.

Hon NICK GOIRAN: I conclude my remarks on clause 7 by noting that the government intends to continue to allow a plenary guardian to consent to the sterilisation of a represented person.

Hon AARON STONEHOUSE: Looking at the prohibitions under section 45 that apply to a plenary guardian and what they can and cannot do on behalf of a patient, I notice that the list is not particularly comprehensive. It spells out a few things they cannot do such as vote in an election or adopt children or solemnise a marriage et cetera. Proposed new section 45(4A) states —

> A plenary guardian —
>
> (a) cannot consent, for the purposes of medical research, to —
>
> (i) the sterilisation of the represented person; or
>
> (ii) electroconvulsive therapy …

Has the government given thought to putting in a head of power for regulations to be written to prohibit other types of activity that a plenary guardian cannot carry out or consent to on behalf of a patient? It strikes me that

circumstances that we have not considered may arise in the course of medical research—technology and treatment types that have not been invented yet—that may be ethically questionable for a plenary guardian, and, perhaps, the other types of decision-makers that the bill prescribes later, to consent to on behalf of a patient who is incapacitated.

Hon SUE ELLERY: No. The government is not considering creating a regulation-making power to capture, if I can use that word, future things that this guardian or any other guardian might be asked to make a decision on. No, we are not. However, I draw the member's attention to the fact that there is a proposed statutory review of these provisions at the 12-month mark, there is a reference to a committee in the Legislative Assembly, and, in due course, the chamber will give consideration to referring the bill to the Standing Committee on Legislation. Any number of things may come out of those three processes.

Hon AARON STONEHOUSE: I thank the minister; she makes a good point. There will be ample opportunity to review this if the chamber agrees to a sunset clause and in due course makes a referral to a committee. That would provide me with some comfort. This may be an appropriate place to have a regulation power, but that is something that we can consider at a later stage. I am satisfied that in future reviews we can, hopefully, look at that matter and consider whether it is worthwhile including.

Clause put and passed.

Clause 8: Section 51 amended —

Hon NICK GOIRAN: One of the outcomes of this clause is to strengthen the obligation of the guardian by using "must" instead of "shall". Is this an issue anywhere else in the act?

Hon SUE ELLERY: We are not going to do a word search now and check where else this word may appear in the act. I am advised that this is a style matter as opposed to a policy matter, which I think is what the member was suggesting. It is a style matter that has been picked up by parliamentary counsel.

Clause put and passed.

Clause 9: Section 55A amended —

Hon NICK GOIRAN: In what circumstances would a guardian appointed under a guardianship order not be the research decision-maker that this provision seems concerned to prohibit from making a decision?

Hon SUE ELLERY: In the event that it is a limited guardianship.

Hon NICK GOIRAN: To expedite time, does this concern also apply to the enduring guardian and explain the desire for clause 11?

Hon SUE ELLERY: I cannot give the member a definitive answer about whether or not there is a capacity for a limited enduring guardianship. I am sorry but I cannot clarify that for the member.

Clause put and passed.

Clause 10 put and passed.

Clause 11: Section 110I amended —

Hon NICK GOIRAN: In picking up the dialogue under clause 9, the minister will see that the same language is being used here. The government's intent is to specifically address a concern or a mischief; therefore, clause 11 inserts proposed section 110I(1A). My reading of the provision is that it seems to be necessary only if there are circumstances in which an enduring guardian is not the research decision-maker. However, it is not clear to me in what circumstances that would apply. Can I have an explanation of why clause 11 is needed?

Hon SUE ELLERY: It might be because they are not available. For example, they are not here; they might be away—all of those sorts of circumstances.

Hon NICK GOIRAN: If they are not available, they cannot make the decision. This is referring to power that may be exercised only if the enduring guardian is the research decision-maker for the appointor. Would the enduring guardian not always be the research decision-maker for the appointor?

Hon SUE ELLERY: The honourable member might recall that I referred to this, I think, in my second reading reply. There are provisions in the bill that relate to the enduring guardian not being available. I take the member to proposed section 110ZP, "Term used: research decision-maker", and subclause (2), which states —

> … applies to a person who is —
>
> (a) an enduring guardian …
>
> (b) authorised to make a research decision …

(c) reasonably available; and

(d) willing to make a research decision …

That is in the event that the enduring guardian is not reasonably available or willing to make a research decision, and why I gave the answer that I did earlier.

Hon NICK GOIRAN: The circumstance we are concerned about is that an enduring guardian might not be happy for the person to have experimental non-standard treatment—whatever language we want to use. If the enduring guardian says that they are not willing to make a research decision for this candidate, that triggers the cascade to other people in the hierarchy.

Hon SUE ELLERY: I will get the member to read the last bit. He is quite right; they might not be willing to make the decision. That is explicitly provided for in the bit that I just read out; they might not be willing. The point that has been made is they are still making a decision, and it might be a negative decision.

Hon NICK GOIRAN: We are on the same page there, minister. This is my concern. The person cannot give consent. Let us assume that they are unconscious. An enduring power of guardianship is being provided. The enduring guardian has been entrusted by that person, when they previously had capacity, to say, "I want you to make decisions for me." That person says, "No problem. I am making a decision: I don't want experimental treatment on you", and that is considered to then trigger the right for the medicos and the like to go down the cascading order and look for somebody else to make the decision. The point here is that they have therefore made the decision. They have said, "I don't want this to happen; I'm unwilling to act." I am troubled by this. I can see we will not go anywhere fast on this today, but this might be something that warrants further scrutiny by the various mechanisms that are being proposed.

Hon SUE ELLERY: I am not sure whether we are going to be able to finalise this. "Willing to make a decision" is different from willing to make a particular positive or negative decision.

Hon NICK GOIRAN: The question would then be: what is contemplated? Someone has decided to put "willing to make a research decision" in proposed section 110ZP(2)(d). Somebody decided that that was sufficiently important. We will get to that when we get to clause 12, but I put it on notice so that those who are providing advice can give some consideration to that. It is not clear to me why it would be appropriate. If an enduring guardian says they are not willing to make a research decision for that candidate, that is the decision—they are not going to perform research on that person. As I said, let us look at that in a later clause.

Clause put and passed.

Clause 12: Part 9E inserted —

Hon AARON STONEHOUSE: I have a couple of questions around "independent medical practitioner". Proposed paragraphs (a), (b), (c) and (d) describe what an independent medical practitioner is not. I notice that it is lacking some of the protections that, for instance, the voluntary assisted dying legislation had. For instance, proposed section 110ZO(c) says that an independent medical practitioner —

> is not the spouse, de facto partner, parent, grandparent, sibling, child or grandchild of the research candidate whose participation is sought in the research;

However, it makes no mention of the independent medical practitioner being a beneficiary in the will of a potential research candidate. There is also no prohibition on the independent medical practitioner having some kind of relationship with the researcher. Although there is a prohibition on the independent medical practitioner being involved in the research, there is no prohibition on the independent medical practitioner and the researcher being intimate partners, siblings or having some other kind of business arrangement. I understand that it is likely that in a hospital they would be employed by the same employer, but I just see some glaring differences between the independence of a medical practitioner here and the independence of medical practitioners in similar legislation such as the voluntary assisted dying legislation.

Hon SUE ELLERY: "Medical practitioner" is defined further on in proposed section 110Z0. The definition states —

> ***medical practitioner*** means a person registered under the *Health Practitioner Regulation National Law (Western Australia)* in the medical profession …

There are professional obligations that apply to all medical practitioners that go to the issue of conflict of interest that the member raised, and that applies to all medical practitioners. If the reference the member just made is read on top of those, these things are specified in addition.

Hon AARON STONEHOUSE: I appreciate that there are codes of conduct and ethics that medical practitioners must abide by, but I am not so sure that they are always sufficient. If they were always sufficient, there of course

would not be a need for us to spell out what an independent medical practitioner is in this case. Nonetheless, it is something I hope that a future committee would look into and that a future Parliament, if reviewing this legislation in four years' time, would look also into.

Hon NICK GOIRAN: Does clause 12 implement recommendation 6.1 of the statutory review?

Hon SUE ELLERY: Proposed section 110ZR, which is not the one we are looking at now, gives effect to recommendation 6.1. Proposed section 110ZS is contrary to recommendation 6.2.

Hon NICK GOIRAN: Sorry, did the minister say that it is not the one that we are looking at now?

Hon Sue Ellery: We are on proposed section 110ZO.

Hon NICK GOIRAN: No, we are on clause 12.

Hon SUE ELLERY: Yes, proposed section 110ZR, which is part of clause 12, gives effect to recommendation 6.1. If it is of assistance to the honourable member, proposed section 110ZS in clause 12 is contrary to recommendation 6.2.

Hon NICK GOIRAN: This goes to the question that members may recall I asked under clause 1. I draw to members' attention that I asked the minister which of the statutory review's 77 supported recommendations were implemented by this bill. *Hansard* will reflect that some exchange took place at that point. There was some bristling at the possibility that I was asking those questions. Eventually it became clear that two recommendations were being implemented and the minister kindly identified for us recommendations 6.1 and 7. I agree with what the minister said eventually in clause 1 and that those things have been implemented at the respective clauses that have been identified. Members may also recall that I asked: does the bill do anything to which the statutory review expressly recommended against? There was seemingly some outrage that I would ask that. I indicated that it was very important because I wanted to know which clauses of the bill I might be supporting were expressly recommended against in the statutory review. Now we find out at this late hour that the exact opposite to recommendation 6.2 in the statutory review is being done. Members may not be familiar with recommendation 6.2, so I will quote it now. It states —

> Health professionals acting under the urgent provisions in sections 110Z1 and 110Z1A will not be permitted to make a decision on behalf of a represented person for that person to participate in medical research, including treatment that is part of research.

For any other members who voted against the bill at the second reading, or any members who are concerned about this bill—in particular, about proposed section 110ZS—and any member who has been lobbied heavily over the past few days, or even the past few hours, and urged to support the bill, let us be clear: by supporting the bill in its current form, we are supporting something that the statutory review expressly said "do not do". Maybe now some of the cooler heads will understand why this bill has been causing some problems over the past week or so in the various versions that have been put forward. At this point I commend Hon Michael Mischin, who has on the supplementary notice paper an amendment to ensure that there is a sunset clause for this exact provision—proposed section 110ZS. We have now found out for the first time from the government that that provision will do the exact opposite of what the statutory review said to do. During the coming five-week parliamentary recess, I look forward to reviewing the *Hansard* of debate on this bill in the other place yesterday to see whether on any occasion whatsoever any member of the government drew to the attention of members that what they were doing was supporting something that the statutory review said not to do. I look forward to doing that.

That should have been said in the second reading speech. It is a disgrace that the second reading speech tells us that the government is implementing recommendations from the statutory review, but hides from the fact that it is doing something that the statutory review said not to do.

I have some further questions on clause 12. I take the minister to proposed section 110ZR. There is reference made there to advance health directives, particularly in proposed section 110ZR(4), which is found on page 16. My question really follows on from some concerns raised by Hon Alison Xamon in her second reading contribution to confirm that proposed section 110ZR(4) gives primacy to a patient's wishes as evidenced in their advance health directive. I have a particular interest in it because I know that the version of the bill that I saw on Monday, which was draft 14, did not have that in there. I raised that in the course of my Zoom briefing on Monday, and I take this opportunity to commend the various people involved, including the Solicitor-General, for taking up that cause. I see that it now appears in the bill before us, and I am grateful for that. However, like Hon Alison Xamon, I would still like to have confirmation on the record at this time, when we are debating clause 12, that it will give primacy to the patient's wishes as evidenced in their advance health directive.

Hon SUE ELLERY: Yes, and, as the honourable member indicates, it is in there as a direct result of the suggestion that he made.

Hon AARON STONEHOUSE: I am just wondering whether there is a statutory definition for someone who is able to make reasonable judgements, or otherwise unable?

Hon Sue Ellery: Can the honourable member just point me to where that expression is used?

Hon AARON STONEHOUSE: It is used in proposed section 110ZS(1)(c). It seems to be the main criteria for assessing capacity. However, looking through the bill with a keyword search, I was unable to find a clear definition of what would make a candidate or patient unable to make reasonable judgements, or how that might be tested.

Hon SUE ELLERY: There is not a statutory definition. It is a medical assessment to be made, and there might be all sorts of variations on the spectrum of what circumstances the medical professional will look at in determining whether a person is able or unable to make reasonable judgements. It is not possible to define that; that is a judgement to be made by a medical professional.

Hon AARON STONEHOUSE: I appreciate that there might be some subjectivity in this kind of stuff, but it is a little concerning to me. We are not talking now necessarily about capacity; rather, we are talking about whether or not someone's decisions about their own health care are reasonable. Someone might make the argument that an anti-vaxxer—someone who refuses to vaccinate—is making unreasonable judgements about their own health, and I would agree with that assessment, but it certainly would not seem to fit within the type of scenario we are imagining here, where someone is incapacitated. The language that has been used consistently in the debate on this bill has been around capacity—someone who is incapacitated and not able to make their own decisions—whereas here, the language used is more around the reasonableness or otherwise of the decisions that they make, so someone who is not particularly well informed or has been given misleading information might make unreasonable decisions. Someone in shock might make an unreasonable decision. If this appears in another statute somewhere and the minister can point me to it, or some other examples where I might get an idea of how it is used, that might be helpful, or if there is some common law definition, that might be helpful, too.

But I do not think it is sufficient to merely rely on how the medical profession interprets such a phrase. Although it may be important how the medical community carries out their duties under this act, at the end of the day, what will be more important will be how the courts interpret this if there are any problems. I think we need to be really, really careful here about what that actually means from a statutory interpretation perspective.

Hon SUE ELLERY: Does the honourable member have the substantive act?

Hon Aaron Stonehouse: I do.

Hon SUE ELLERY: I take the member to part 2, "Principles to be observed by State Administrative Tribunal", and section 4(2), which states —

> The primary concern of the State Administrative Tribunal shall be the best interests of any represented person, or of a person in respect of whom an application is made.

Subsection (3) states —

> Every person shall be presumed to be capable of —
>
> (a) looking after his own health and safety;
>
> (b) making reasonable judgments in respect of matters relating to his person;
>
> (c) managing his own affairs; and
>
> (d) making reasonable judgments in respect of matters relating to his estate,
>
> until the contrary is proved to the satisfaction of the State Administrative Tribunal.

The language used to explain how the State Administrative Tribunal, for example, applies its decision-making to a range of matters captured under the Guardianship and Administration Act is used elsewhere.

Hon AARON STONEHOUSE: I thank the minister. I read that earlier, and although I am pleased to see that there is a presumption of someone's ability to make reasonable judgements, it does not clearly define what is a reasonable judgement or otherwise, at least not to my satisfaction. It is a little concerning. It would be helpful if the minister could point us to a court decision about this, but otherwise I remain a little unclear as to what that means. Hopefully, those carrying out their duties under the act are guided by other tests of capacity that exist in other acts, but for now this remains a big unknown and it leaves me rather concerned about how we might deal with people with a mental illness, for example, who might legally have capacity but might not reach the threshold of being able to make a reasonable judgement, at least in the eyes of a medical practitioner or a researcher. If we cannot address this now, hopefully it will be addressed by a future Parliament or a standing committee that has an opportunity to inquire into this bill.

Hon SUE ELLERY: The point I was trying to make is that the term "reasonable judgement" is already used in the Guardianship and Administration Act without a definition. Although that might not be satisfactory to the member, the point I am trying to make is that that language is not new and it is not a function of the particular provisions

for treatment for the purpose of medical research. That is the point I was trying to make. It is not a term that has been invented for the purposes of what is before us today.

Hon AARON STONEHOUSE: I take that point. It is not a new term. The bill uses the language that already exists. However, my concern remains in that we are opening the door to medical research and experimental treatment in this case. I would have expected a harder definition or a higher threshold in this case. I will not labour the point. I will leave it there for now so that other members have an opportunity to ask questions.

Hon NICK GOIRAN: Further to this issue of advance health directives, and specifically with respect to proposed section 110ZS, which is the section that is being implemented contrary to the recommendations of the statutory review, the bill states that the researcher "ought reasonably to be aware" of a patient's advance health directive. Under what circumstances would it be considered that a researcher "ought reasonably to be aware" of a patient's advance health directive but was not aware of their advance health directive?

Progress reported and leave granted to sit again, on motion by Hon Sue Ellery (Leader of the House).

[Continued on page 2059.]