

GUARDIANSHIP AND ADMINISTRATION (MEDICAL RESEARCH) ACT

Grievance

MR S.A. MILLMAN (Mount Lawley — Parliamentary Secretary) [9.56 am]: My grievance this morning is to the Attorney General and it concerns medical research, a matter that I have raised with his cabinet colleagues—namely, the Minister for Health, Amber-Jade Sanderson, and the Minister for Medical Research, Hon Stephen Dawson. I would like to thank those of my constituents who are expert medical and legal practitioners and have raised this issue with me. It concerns amendments to the Guardianship and Administration (Medical Research) Act 2020. On Tuesday night, I was fortunate enough to be at the Spinnaker Health Research Foundation awards, when CEO Dana Henderson and chair Andrew Friars, together with the chair of the South Metropolitan Health Service, Associate Professor Robyn Collins, and the CEO, Paul Forden, were unanimous in commending the work of the state government in supporting medical research as a key pillar to ensuring that we retain our world class health system. People at the research awards night universally made the point that supporting medical research is imperative if we are going to maintain our standard of care. This morning I was at a Palliative Care WA symposium where people who are looking at end of life re-emphasised the importance of consent to participate in certain medical procedures, and more emphasis was placed on advance health directives. I thank the Attorney General for providing me with the opportunity to chair the Ministerial Expert Panel on Advance Health Directives during the last term of Parliament so that we could make access to advance health directives easier, more commonplace and more well known throughout the community. In so doing, we provided the framework within which people can make appropriate choices for their end-of-life care.

That creates the context in which I would like to highlight the problem. When this McGowan Labor government introduced world leading amendments to the Guardianship and Administration Act at the height of the COVID pandemic in 2020 to facilitate more effective medical research, we amended section 110ZS, which provided for urgent medical research without consent within the Guardianship and Administration Act. Through my involvement in the Ministerial Expert Panel on Advance Health Directives that I just referred to, I have been fortunate enough to meet many incredible medical experts and researchers in our state who work tirelessly to keep our state and communities within our state safe and strong. In that regard I would like to give special mention to those who have raised this issue with me. From the Australasian College for Emergency Medicine I acknowledge both Peter Allely and Daniel Fatovich who have regularly talked to me about this issue. I also acknowledge Professor Tony Celenza. These people have identified just how important preserving this provision in our Guardianship and Administration Act is to ensure that the medical research that is being facilitated under this amendment can continue.

Just by way of background, although the previous legislation allowed for a guardian and next of kin to consent to medical treatment, as that term was defined, nothing permitted them to consent to participation in medical research. Because the treatment of COVID-19, by necessity, involved medical research, this meant we had to implement these legislative changes as a matter of urgency.

Section 110ZS is a vital part of fixing this because it enables medical research to occur that can save lives during a medical emergency. As the Attorney General would know, a wide range of conditions in emergency departments can lead someone to require urgent medical treatment without consent such as cardiac arrest, stroke, major trauma and septic shock. In modern medicine, the concept of treatment has evolved to rightly recognise the importance of all forms of research from surveys and interviews to non-intrusive interventions such as X-rays, blood samples and administering fluids through a drip. Clinical trials that involve these kinds of research are not only important for discovering and developing new ways of treating patients or new kinds of illnesses, but also necessary for improving and updating existing practices.

Due to the legislative changes that were passed by this government, Western Australian researchers have been able to conduct a comparative effectiveness trial that found that outcomes were much more positive for patients over the age of 65 years who did not receive treatment involving medicine than those who did. WA is now one of the leading sites around the country for this trial and this research will save and improve thousands of lives around the world every year. The article I referred to for that information is the *Tasman Medical Journal*, volume 4(2), 2022, “Keeping ethics at the forefront of medical research: the Guardianship and Administration Amendment (Medical Research) Act (WA) 2020”. Amongst the authors of that article was the eminent legal mind of Hon Eric M. Heenan, QC, who I know has raised this matter with the Attorney General as well as with me.

My grievance this morning concerns the unfortunate behaviour of Hon Nick Goiran in the upper house and his insistence on imposing a sunset clause on what is otherwise widely commended legislation. My concern and that of the legal and medical experts who have raised this matter with me is that the operation of the sunset clause will stand in the way of this groundbreaking, world-leading medical research. My grievance is that members of the Liberal Party who like to say that they support our health system behave in a way that is entirely inconsistent with that when people like Hon Nick Goiran place barriers in the path of medical research that makes it harder for our expert clinicians, academics and medical researchers to do their work. This issue has been raised with me by

medical experts, researchers, clinicians and legal experts. They have asked me to ask the Attorney General to provide us with an update on the government's position on these excellent amendments and what the future may hold for the safety of medical research in Western Australia. I thank the Attorney General for taking my grievance.

MR J.R. QUIGLEY (Butler — Attorney General) [10.02 am]: I am deeply appreciative of the member for Mount Lawley's vital interest in this matter through the passage of the Guardianship and Administration Amendment (Medical Research) Bill 2020 and during this review of the act. As the member mentioned, the Guardianship and Administration Amendment (Medical Research) Act 2020 was passed in April 2020 during the early days of the COVID-19 pandemic. Although the act was presented before Parliament in extraordinary circumstances, the work behind the legislation had been the product of years of community and stakeholder consultation and reflects our commitment to the principles of good governance in supporting and investing in our state's healthcare system.

Back in 2015, the Department of the Attorney General conducted a statutory review of the Guardianship and Administration Act 1990 to assess the operation and effectiveness of the amendments made by the Acts Amendment (Consent to Medical Treatment) Act 2008. Having consulted the Public Advocate, the Public Trustee, the Department of Health and over 163 government and non-government agencies, health services and medical ethics committees, the statutory review found strong support to amend the guardianship act to allow consent to medical research treatment for people temporarily or permanently incapacitated under guardianship orders. The Guardianship and Administration Amendment (Medical Research) Act enables medical research to be conducted in respect of people without the capacity to consent. An incapacitated person may participate in research in two circumstances. First, with the consent of their decision-maker or, second, in urgent situations without prior consent. Various safeguards ensure that enrolling an incapacitated person in urgent medical research is subject to independent oversight and review. Researchers are permitted to conduct research approved by a human research ethics committee. This can occur only if an independent medical practitioner has determined that the research is in the best interests of the patient or is not averse to the interests of the patient by increasing his or her medical risks.

As the member for Mount Lawley noted, the sunset clause was included in the bill and is due to take effect on 8 April 2024. As the member noted, this was included at the insistence of Hon Nick Goiran in the upper house, and, as I said to Professor Danny Fatovich at the time, we cannot let perfect get in the way of good. We had to get the bill through. Politics is about the art of what is possible. At that stage back in 2019, Labor's views did not always carry in the upper house—such is not the case today. As I said, the bill contained a review clause that the other chamber, at the behest of Hon Nick Goiran, changed into a sunset clause. Under that clause, I am required to review the operation and effectiveness of the medical research amendments in accordance, as the member for Mount Lawley said, with section 110ZZE of the Guardian and Administration Act 1990. As the member outlined, the review is well underway and has benefited from the expertise of a project reference group. The reference group comprises representatives of the Department of Health, the Office of the Public Advocate and the Department of Justice. The department consulted a wide range of stakeholders including medical researchers, patient advocacy groups and mental health, disability and aged-care sector representatives. The review is considering the view of those stakeholders given their practical knowledge of the legislation.

Member, the review is in its final stages. I expect that the final report will soon be presented for my consideration. I assure all members that the review has carefully considered the sunset clause in light of the concerns raised by the member and other medical researchers. I have a personal interest in this matter having been the beneficiary of medical research when I was diagnosed with T-cell lymphoma back in the day. Earlier in my parliamentary career, I was a bit lost in Western Australia because no research had been done into that rather obscure or rare disease. I enrolled in a medical research program in Melbourne along with nine other people, and it is because of my participation in that medical research and in that trial program that I am standing here today addressing this grievance.

I wish to assure all members and any medical researchers who might read the transcript of the member for Mount Lawley's grievance this morning that I have a particular ongoing and enduring interest in this issue. I am waiting for the final report to be presented and we will address the sunset clause in due course. I will keep the chamber and members updated. I know that it is crucial to the advancement of our health system and the health of all Western Australians that our health system and the researchers and practitioners within it are at the cutting edge of cures for disease in Western Australia. I thank the member for raising this important issue.