

Opening Statement to the Oireachtas' Joint Committee on Assisted Dying 24 January 2024

Introduction

My name is Ben White and I am Professor of End-of-Life Law and Regulation in the Australian Centre for Health Law Research at the Queensland University of Technology in Brisbane (Meanjin), Australia. I also make this opening statement on behalf of my colleague, Professor Lindy Willmott, as together we have been researching the law, policy and practice of voluntary assisted dying for over 20 years. More information about our work is at the end of this statement.

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We support law reform to allow voluntary assisted dying in limited circumstances. It is possible to design a safe and effective voluntary assisted dying system that respects autonomy and shows compassion for terminally-ill patients who are suffering and want to die, while at the same time robustly protects the vulnerable in society.

Reaching this view required a process of deliberation. First, we reflected on the ethical values that we thought should underpin law in this area: the values of life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, reducing human suffering, and safe and high-quality care. We balanced and weighed these values and concluded that the ethical case for lawful voluntary assisted dying was very strong, provided it can be done safely.

Whether voluntary assisted dying can be safe involves a shift from ethics to facts and importantly, consideration of the evidence. We reviewed the evidence, including two decades of experience in places overseas which showed that vulnerable individuals are not more likely to use voluntary assisted dying, and also that voluntary assisted dying can be regulated safely.

This was the view we reached prior to voluntary assisted dying becoming lawful in Australia. Since then, all six Australian states, after careful reviews by committees like this one, and extensive debate in all six parliaments, decided that it was safe to have voluntary assisted dying. So we can now add the experience in Australia to that evidence.

After reviewing the four years of experience in Victoria, two years in Western Australia, and about one year in Queensland, South Australia and Tasmania (New South Wales' law has only recently started), our view remains that voluntary assisted dying can be safe, and that this is the case in these systems. The Australian evidence we draw on for this includes the reports of the oversight bodies in these states. It also includes our research (with team members) across the states of Victoria, Western Australia and Queensland interviewing over 140 people: people seeking voluntary assisted dying, their family members, doctors, nurses, pharmacists, health administrators, medical college members, oversight board members, government officials and others. A key finding from this research is that the voluntary assisted dying systems are operating safely. In fact, a challenge is that the many safeguards in these systems have made accessing voluntary assisted dying very difficult for some patients.

Law reform deliberations should be evidence-based, using evidence that is reliable

I conclude with some reflections on research we have done on law reform deliberations about voluntary assisted dying. In this research, we make the case for such deliberations to be evidence-based and, in particular, that the evidence which law-makers use be reliable.

I mentioned our own process of deliberation about voluntary assisted dying involved thinking first about the ethical issues and then about the facts or evidence. People can and do reasonably have different views about ethics – the rights and wrongs of voluntary assisted dying. This is informed by a person's values, and we stated transparently the values that we considered in our deliberations.

But arguments about facts are different – these are claims about whether or not something is happening in practice. An example is: are vulnerable groups in society more likely than others to seek voluntary assisted dying? This question, because it is about facts, is not settled by debating values, but rather by looking at the evidence.

A key challenge for this committee is that you have received, and will continue to receive, a lot of information that will conflict: voluntary assisted dying is said by some to be safe and by others to be dangerous.

We make this point about evidence: only reliable, trustworthy, high-quality evidence will accurately show what is happening in practice. Drawing on established ways that science uses to evaluate evidence, a ‘reliability’ pyramid has been proposed by a colleague Professor Jocelyn Downie (which is Figure 1 at the end of this statement).

At the bottom of that pyramid are anecdotal claims or opinions – what people claim to have seen or what they believe based on their experience or views. These claims are of limited reliability and are not a safe basis on which to make laws.

An example towards the top of the pyramid is a systematic review, published in a top international journal and subjected to peer review, which analyses all the research done on a topic and critically evaluates it. This is reliable evidence which law makers can safely act upon.

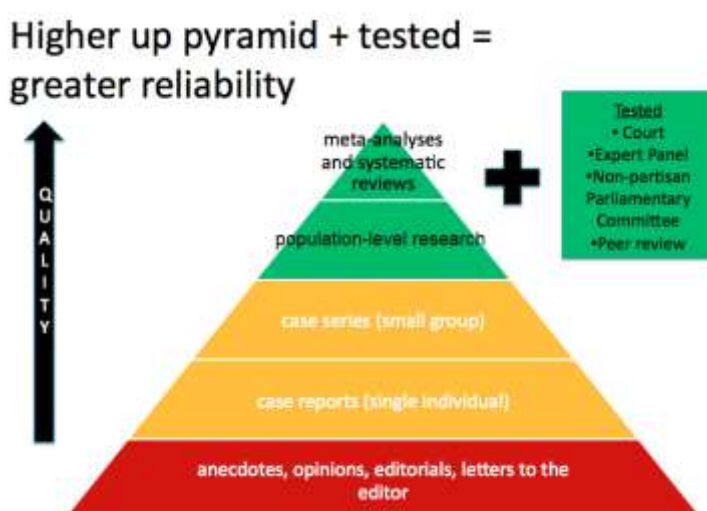
I conclude by noting that this point about evidence is not an argument in favour of or against voluntary assisted dying. It is rather an argument that law-makers, when considering this important and complex topic, should be supported in their deliberations by high quality, reliable evidence.

Background information

Ben White and Lindy Willmott are health law professors whose principal area of research expertise is end-of-life law, policy and practice, particularly voluntary assisted dying. We have each been researching in the end-of-life area for over 20 years. We have published over 150 publications on end-of-life decision-making and received over \$65 million (Australian dollars) for end-of-life research and training programs. We were commissioned by the state governments of Victoria, Western Australia and Queensland to design and deliver the legislatively-mandated training for practitioners wishing to provide voluntary assisted dying. Our current work includes a four-year project funded by the Australian Research Council's Future Fellowship program entitled 'Optimal Regulation of Voluntary Assisted Dying': <https://research.qut.edu.au/voluntary-assisted-dying-regulation/>.

We have been consulted and participated in various voluntary assisted dying law reform exercises in Australia and overseas. We also edited the book *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021). This collection includes ten case studies of end-of-life law reform, including voluntary assisted dying, from six jurisdictions: United Kingdom, United States, Canada, Australia, Belgium and the Netherlands.

Figure 1*



* Drawing on work of Jocelyn Downie at http://eol.law.dal.ca/?page_id=966 and published in: BP White and L Willmott (2020) Evidence-based law making on voluntary assisted dying. *Australian Health Review*, 44(4), pp. 544-546.