

Submission to the University of Tasmania Review of *End-of-life Choices (Voluntary Assisted Dying) Bill 2020 (Tasmania)*

Name : Frank Brennan. I am a Palliative Medicine Physician and lawyer, based in Sydney, NSW.

My qualifications are: MBBS, DCH (Diploma of Child Health), Dip Obs (Diploma of Obstetrics), FRACP (Fellow of the Royal Australasian College of Physicians), FACHPM (Fellow of the Australasian Chapter of Palliative Medicine), LLB (Hons) ANU. I was an Associate to Justice Mary Gaudron, justice of the High Court of Australia.

My submission ¹ shall be in two parts:

A. The challenge of VAD legislation and medicine.

B. Specific issues in the *End-of-life Choices (Voluntary Assisted Dying) Act 2020*. Tasmania (hereafter referred to as “the Act”).

Challenge of VAD legislation and medicine

Law aims for precision. Medicine, on the other hand, operates in a landscape of uncertainty. So when the two disciplines meet to focus on issues vital to voluntary assisted dying (VAD) legislation, such as prognostication, decision making capacity, the possibility of undue influence, screening for depression and the use of life-ending medications (with likely inter-individual variability in effect), there may be problems. As physicians, we know we cannot be certain about these issues. The laws strains to achieve certainty in language and effect. The law seeks, but medicine cannot provide, such certainty. And yet, with VAD, both disciplines are highly conscious of the irreversible consequences for not getting things right. There is, therefore, an inherent tension at the centre of any VAD law. For law is entering the two domains : medical uncertainty and the mystery of the human psyche and interpersonal relationships. Uncertainty and mystery are not solid foundations for any legislation.

All VAD laws, including the Tasmanian Act, face a series of identical challenges. Those challenges are significant and, arguably, insuperable. Challenges include the criteria of eligibility; prognostication; the assessment of capacity; ensuring the person is not acting under undue influence; the role of

doctors, nurses and pharmacists in the process; the role, if any, of Palliative Medicine and Psychiatry and the structure of the process leading up to the final act. Flowing from that are the medical questions that pour out upon this landscape to make this exquisitely vexed area even more problematic for doctors. What lethal medications are used and in what doses? What level of training in counselling, communicating and the use of these medicines should occur? What happens if there is a complication? How prepared is any doctor to commit an act, however legal, that has hitherto been completely contrary to both the law and professional ethics? Ultimately, what will the experience of the patients, families, doctors, nurses and pharmacists involved in this process? Away from the glare of the public debate, their encounter will be intimate and intense. No law, no public campaign, no training can ever truly prepare the participants.

Each of these challenges is substantial. Each of these questions represent the sheer complexity of a legally-prescribed process that now sits in a domain that is already challenging and mysterious – the profoundly human experience of becoming seriously ill, balancing hope and realism, enduring and hopefully overcoming symptoms, facing one's own mortality, gazing with penetrating eyes at the meaning of your life, comforting and being comforted. No law can use this language and yet that is the reality of our work as physicians. Discussion, negotiation, compromise. And there lies the rub. Law grapples earnestly with this area and seeks to marshal multiple safe guards in the process leading to VAD. But by having, as its destination, the planned, premature death of a person, the law ventures into medical uncertainty, the vagaries of human nature and the extraordinarily complex nature of interpersonal relationships. Of minds made up and then changed. Of the ebb and flow of the human spirit, despairing now, content a day later. Of a selfless impulse, in some, to ease the burden on one's family. Of a life-time habit, in others, of acquiescing to the suggestion, even unspoken, of a dominant relative.

In addition to this struggle, the legalisation of VAD does another thing that is striking in both intent and effect. By such statutes, including this Act, the law crowns autonomy king. Every VAD law starts and finishes with the express wish of the eligible person. Every physician knows that we cannot give everything a patient wants or insists upon. We know that autonomy, however revered, is one of several guiding principles and while we listen to patients, our responsibility is to always carefully weigh the benefits and burdens of treatment. And so, if, in this one area of medicine, autonomy trumps all else, where that supremacy is legally sanctioned over and above other principles or

approaches, then there is a problem for law, medicine and ethics. These are solipsistic times. By the present law, the “we” in all of us is subsumed by the “I” in some of us. The “I” is placed pedestal-high, such that it purports to oversee death itself and the dangers inherent in that coronation are ignored or set aside.

Specific issues

Capacity

In the Act, a vital criteria of eligibility is capacity. There are challenges in such assessment in the context of serious illness. Discerning capacity can be difficult and even when the person is referred to a psychiatrist, that discipline itself concedes that while “the expectation that the assessments [of capacity] will be definitive... in reality, they are a process, complex in nature, and inherently uncertain.”²

The law provides further relevant examples. In *Re T* and *Re MB*, the courts found that pain, fear and fatigue could be so severe that they could disturb the ability of a patient to reason.^{3 4} In this context, the Act contains a conundrum. One of the eligibility criteria is that the person is suffering intolerably in relation to the relevant medical condition, that there is no reasonably available treatment likely to improve the condition or overall health and wellbeing and “in the opinion of the person, lessen the person’s suffering to an extent that is acceptable to the person.”⁵ It is quite possible that such a level of suffering as described, equally disturbs the ability of the person to think rationally.

Palliative Care

Under the Act neither a referral to, nor assessment by, Palliative Medicine is a mandatory part of the VAD process. Certainly, the Act states that a person approaching the end of life “should be provided with high quality care and treatment, including palliative care...”⁶ That statement is an aspiration. It may or may not occur. Under the Act, the entire VAD process could occur without palliative care. The Act permits a doctor to initiate a discussion about VAD as long as that discussion is coupled with information to the patient about treatment options and: “the palliative care and treatment options available to the patient and the likely outcomes of that care and treatment.”⁷ The law assumes that a reasonable body of knowledge about this discipline is universal in medicine. In reality, the doctor who give this information may have little or no knowledge of Palliative Care or its outcomes. At this juncture clinicians,

patients and families may be adrift on a sea of myth. The patient, therefore, may make a decision to pursue the process without being fully informed. Logically, this leads to a basic question: how can one make a decision, as fatally serious as this one, without being fully informed about the very discipline of medicine that is dedicated to the management of life-limiting illnesses? Simply stating the existence of the discipline does not explain it. It is ironic that a campaign and legislative objective that trumpets autonomy and the power of choice may lead to a situation where a person is insufficiently informed in their decision-making.

Information is one thing. Experience is another. In the Act, one of the criteria of eligibility is the subjective intolerability of suffering, both current suffering and anticipated suffering.⁸ In reality, this is often the point where Palliative Care enters the scene now. It does so to bring a powerful and forensic approach to these issues and their management, attentive to, and understanding of, the rhythms of both the disease and the human spirit. Instead, under the Act, the eligible person embarks on an altogether different journey. Process dominates; seeing a Palliative Care physician is optional. The patient decides on the point when things are intolerable but that decision may never have been informed by the actual experience of receiving Palliative Care. The Act places into the patient's hands the ability to commence a process that may lead them to a premature death where that patient has not engaged with medical experts who could deal with, assuage or comfort the reasons they sought this process in the first place.

The inclusion of *anticipated suffering* in the Act marks a significant shift in Australian VAD laws. The experience of Palliative Medicine is that patients can imagine multiple scenarios that may never occur. That imagined future may be based on what they have heard or witnessed of the death of relatives or friends that may have occurred before the advent of modern Palliative Medicine. Invariably they are not informed about significant modern developments in symptom control and the relief of psychosocial distress. The imagined future of an illness may overwhelm. An important part of our role in Palliative Medicine is sitting with patients and families explaining that suffering is not inevitable, that every death is unique and describing in detail what can be done in response to their suffering. Often, these conversations are a revelation. They are greatly comforting. The disappointing aspect of this Act is that a patient, anticipating future suffering, may proceed with VAD without ever having such a conversation.

Prognosis

The Act sets out criteria for prognosis. Notoriously, doctors struggle with prognostication, even with the best prognostic tools. This is an example of the precision required by the law (6 or 12 months⁹) and the relative imprecision of medicine.

Families

Families may respond to this process in multiple different ways. They may accept the decision. They may even welcome it. Equally, they may have profound misgivings. Families may be shocked. This is especially so as the Act allows the person to withhold consent from information being provided to their family about the process.¹⁰ Platitudes said to the family later, soaked in the ethos of self-determination, “But that is what he wanted” may be answered bitterly “Yes, but what about his family? Was any consideration given to us?” Grief, already complex, becomes more complicated. The emotional well-being of families may be sacrificed at the altar of individual autonomy.

Moral distress of health professionals

We may never know the emotions of those health professionals involved in this process, the misgivings and moral distress they may experience. For however brilliant the law that is crafted, no law can ever know the heart of a person. A thousand legislative safeguards will never ensure their emotional peace.

Medicine and the response to suffering

There is a further risk to medicine itself. A real risk, in the intermediate to longer term, is that there will be a cohort of participating doctors who are so convinced that they are doing a humane act, that they do not see an alternative. Indeed, that they see VAD as *the* solution to suffering. Gradually, that sentiment may grow. A blindness may develop to the role and capacity of Palliative Medicine that sits and engages with that suffering in an increasingly sophisticated way.¹¹ For that perception to be accepted by medical students and junior doctors, would be deeply troubling. For that sentiment to be accepted by the general public would be equally troubling.

Legal rights

One of the classic refrains in the VAD debate is the importance of a legal right to VAD. A right connotes a duty. In VAD laws there is no duty on a physician to participate in VAD. Certainly, there is an entitlement to VAD for an eligible person.

It is ironic that concurrently with the VAD debate there has been a growing advocacy and, subsequently, recognition within the United Nation of a universal right to palliative care, based, at least in part, on the international right to health.¹² This right has been endorsed by UN Special Rapporteurs, the International Narcotics Control Board (in the context of pain management) and the WHO. Arguably, therefore, the debate on the care of suffering patients could, without controversy, concentrate on the better resourcing and access to palliative care services globally, including Tasmania. Rather than pursuing VAD, the Tasmanian parliament could take a different route in the response the suffering of patients with serious illnesses. Such a deliberate approach, well-conceived, well-researched, coherent and well-funded could be a great example to the rest of the nation and the world.

Conclusion

In conclusion, like all attempts to enact VAD laws, the Tasmanian parliament wrestled with the complexity of eligibility, assessment and process. They were fated to do so. No law, and perhaps especially no law on this topic, can hope to encompass the limitless terrain of the human person and their world in times of serious illness and the medical uncertainties that accompany this. Physicians struggle daily to deal with this. The law is no exception.

Frank Brennan

January 2021

¹ Sections of this submission have been drawn from an article I wrote in 2019: Brennan F. The Victorian *Voluntary Assisted Dying Act* comes into operation. *Int Med J* 2019;49:689-693.

² Bader CS, Hershkopf MD. Trainee Moral Distress in Capacity Consultations for End-of-Life Care. *Psychosomatics* 2018; 1-5.

³ *Re T* [1992] 4 All ER 649.

⁴ *Re MB* [1997] 1 FCR 426.

⁵ *End of Life Choices (Voluntary Assisted Dying) Bill* 2020. Tasmania, s. 14.

⁶ S. 3 (2) (d)

⁷ s. 17 (2)(b).

⁸ s. 14.

⁹ s. 6 (1)(c).

¹⁰ s. 27.

¹¹ Brennan FP. "To die with dignity": an update on Palliative Care. *Intern Med J* 2017; 47(8):865-871.

¹² Brennan FP, Gwyther E. Human Rights Issues in Palliative Care. In: Cherny N et al (eds) *Oxford Textbook of Palliative Care*, 5th ed, 2015, Oxford University Press, Oxford.