Submission
No 65

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

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STANDING COMMITTEE ON LAW AND JUSTICE

LEGISLATIVE COUNCIL, PARLIAMENT OF NSW

INQUIRY

Into the provisions of the *Voluntary Assisted Dying (VAD) Act* NSW 2021

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Thank you for the opportunity to make a Submission to this Inquiry. The content of this Submission is personal and does not reflect the opinion of my employers.

Introduction

My name is Frank Brennan. I am a Palliative Medicine Physician. I am also a lawyer. With great interest, I have followed the process and content of the draft *Voluntary Assisted Dying Act* 2021 (hereafter "the Act") of NSW from two perspectives – law and medicine.

Brief Summary

I shall commence my submission with general observations on the interface of medicine and law. I will highlight concerns about specific areas of the Act, especially the elements of eligibility, the distortion of Medicine by VAD, the paradox of Palliative Care and VAD and the rights based argument.

Law and Medicine

The proposed NSW VAD Act sits at the interface of law and medicine. All laws change society, however minimally. If enacted, the VAD Act represents a profound change in society – to allow for the first time a doctor to, in certain circumstances, cease a person's life or give a person the means to end their life.

Any VAD Act faces an immediate and, arguably, insuperable challenge: to introduce a legal framework into a medical domain of end of life where that domain is replete with uncertainties. The law strives for certainty. Medicine sits with uncertainty. In the context of end-of-life care those uncertainties abound – prognostication, capacity, voluntariness, people changing their minds and the vagaries of family relationships. And yet, these are precisely the areas where the Act attempts to establish eligibility.

Given that the statutory eligibility criteria are critical to the commencement of the VAD process it is important to examine the main criteria carefully.

Prognostication

The Act states that the person must be deemed by their assessing doctor to have a prognosis of 6 months or less or, in the case of a neurodegenerative disease, 12 months or less.

This appears clear. The reality is that determining the prognosis of a patient is notoriously difficult. A major review of the precision of doctors across multiple studies found that clinical prediction of survival is frequently inaccurate. [1] Part art, part science, prognosis relies on both the subjective sense of a doctor (drawing on their experience to estimate how long a person will live) and other objective criteria such as how much time does the person spend in bed, symptoms, the results of blood tests and other factors. International authorities on this subject concluded that "Most clinicians are not taught how to do it well." [2]Even the best, most experienced doctor gets this wrong. Truly, it is not a question of right or wrong, but the doctor doing their best to estimate prognosis and explaining carefully to patients and their families the uncertain nature of this activity.

The usual ramifications of an inaccurate prognosis is a readjustment by the patient to the fact that the original prognosis was not accurate. In VAD, the ramification of an inaccurate prognosis are far more serious. A doctor may assess a patient to have less than 6 months to live and, thus, is eligible for VAD and proceeds to VAD. The law requires that degree of certainty. The risk here is that the doctor may underestimate the time of survivorship. In the absence of VAD, that patient may have lived longer and, in that time, may have lived a whole range of experiences including time with their family.

Capacity

The law presumes capacity of an applicant to VAD. The three elements of capacity are :

(a) Understanding;
(b) Retaining the information, and
(c) Reasoning

The difficulty here is where the disease itself or its treatment may disturb capacity. Persons may seek VAD at precisely the time when multiple aspects of the disease or its treatment may undermine understanding, retaining or reasoning. These include:

- Pain
- Confusion of a sudden onset
- Cognitive effect from treatment (eg. Chemotherapy or Radiotherapy to the brain which may effect concentration.)
- Nausea
- Shortness of breath
- Primary brain cancer or brain metastases (cancer spread onto the brain)
- Major depression
- Raised levels of anxiety about the illness and the future.

The law provides relevant examples. In *Re T* [3] and *Re MB* [4] , the courts found that pain, fear and fatigue could be so severe that they could disturb the ability of a patient to reason. It is quite possible that such a level of suffering as described in the Act, equally disturbs the ability of the person to think rationally. An assessment of capacity is in the judgement of the participating doctors. They may refer to an expert in assessing capacity (usually a psychiatrist) but this assessment is not mandatory. 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." [5]

Voluntariness and undue influence

The Act requires that the person seeking VAD does so voluntarily and without coercion. As meritorious as this requirement is, it means that other forms of influence or pressure, that do not meet this statutory level, may still occur and have some effect on the person. This may be best viewed as points along a spectrum. At one end there is no pressure or influence; at the other extreme is coercion and undue influence. Between those two ends, some degree of influence or pressure may occur that is not picked up within the statutory definition. These influences may be overt or covert.

An example of overt influence would be direct encouragement, such as an adult child saying of VAD "Mum, perhaps it would be for the best." Such a statement would not constitute coercion or undue influence but may, nevertheless, influence the person.

Examples of covert or subtle influence would include :

(a) the person feeling that their family think they are living too long;
(b) picking up on frustration expressed by loved ones;
(c) thinking that others with this level of dependency or loss of control chose VAD so why shouldn't I ?
(d) Absence of adequate medical care including Palliative Care;
(e) Fear of going to a Nursing Home;
(f) That VAD is legal. "Well if society thinks it is OK, then it must be."
(g) Normalising VAD as a way of dealing with suffering. Society's acceptance of VAD as a way of dealing with suffering means that VAD becomes "just another end of life choice." [6]

Each of these pressures may exist in the context of a vulnerable patient. It is the **combination** of:

- Pressures that may not constitute coercion or undue influence but, nevertheless,

are present

- in the context of vulnerability, that is concerning.

What is the nature of this vulnerability ? Vulnerability may have its source in feeling a burden or fearing of being a burden to your family; acknowledgement of frailty; low self-esteem or a history of emotional/physical abuse. Justice Sumption in *Nicholson* in the UK Supreme Court saw such vulnerability broadly :

I very much doubt whether it is possible in the generality of cases to distinguish between those who have spontaneously formed the desire… and those who have done so in response to real or imagined *pressure arising from the impact of their disabilities on other people…it is aggravated by negative modern attitudes to old age and sickness-related disability. Those who are vulnerable in this sense are not always easy to identify (there seems to be a consensus that the factors that make them vulnerable are variable and personal, and not susceptible to simple categorisation).*[7]

In summary, each of the eligibility criteria of prognosis, capacity and absence of coercion or undue influence are subject to uncertainty.

VAD and the distortion of Medicine

For millennia, doctors have been taught that their role is to :

(a) cure patients of disease and, where cure is impossible, to
(b) relieve the suffering of patients, and that
(c) the relief of suffering does not include the intentional taking of a life.

This principle is so fundamental, so central to the practice of medicine. Indeed, it lies in its heart. It is extremely important to note that this is not a religious principle. It is a professional principle.

By permitting doctors to actively cease a person's life prematurely (or give the patient the means to do so through access to lethal medications) the introduction of VAD cuts across this principle. VAD distorts medicine. It shall distort the way medicine is practiced, the content of ethics taught to medical students and the modelling of the complex approach to patients with life-limiting illnesses to students and junior medical doctors. This distortion may have profound unintended consequences for medical, nursing and allied health teams caring for patients. Of her Palliative Care team in Victoria, Associate Professor Odette Spruijt stated :

As a palliative care specialist with over 25 years practice …I have found the institution of the Victorian law to have a devastating effect on my practice of palliative medicine. I have witnessed the devastating impact of this law on the cohesion of teams, on the relationships within clinical units, and as a cause of deep moral distress among many of my colleagues, for whom, this law, and its accompanying narrative, is anathema to the very core of our sense of what it is to be a doctor. [8]

One area of distortion is the tension that may occur between the therapeutic relationship of a patient and their doctor who conscientiously objects to participating in VAD. As two of the most highly regarded Palliative Medicine Physicians in Australia, Professors Brian Le and Jennifer Philip, both from Victoria, stated:

While we believe that directly ending life is a boundary we cannot cross, we also know we cannot abandon our patient at what would clearly be a time of need. Can the doctor-patient relationship survive when electing not to participate ? [9]

> In addition to its effect internally in medicine, it will forever change the way the lay public view doctors. From a position of confidence that doctors would never intentionally cease a person's life to a situation where that was possible, shifts that view. We worry especially for the indigenous community where, already marginalised with historic suspicions of mainstream institutions, that VAD legalisation raises this concern and may result in, as occurred in the Northern Territory when VAD was legalised there, a reluctance to present to doctors, clinics and hospitals.

The paradox of Palliative Care

In the VAD debate, there are several misconceptions about Palliative Care that are used to justify the legalisation of VAD.

An enduring myth is that Palliative Care is already practicing VAD and that be legalising the practice it will be better regulated. . It is not. Families see patients being given morphine towards the end of their life and assume that the morphine is hastening their death. That is incorrect. The standard of care in Palliative Care is to give morphine for symptom management, not simply because the patient is deteriorating. Also, studies have shown that the proportionate use of morphine and sedative medication does not hasten death. [10] [11] These two points are very important : that the discipline of Palliative Care is not already practising VAD by stealth and, secondly, that the standard of care – the proportionate use of medications – does not hasten death.

The Act mandates that the participating doctors, as part of the VAD process, inform the applicant that Palliative Care exists and its likely effect. The concern is the adequacy of the doctor's knowledge. The assumption is that doctors outside of Palliative Care have sufficient knowledge and understanding of the discipline of Palliative Care to give that information. Unfortunately, that is a flawed assumption. Many doctors graduate and work their careers with little exposure to the modern discipline of Palliative Care. Potentially, therefore, this inadequacy of knowledge may weaken this process.

In the Act, a referral to Palliative Care is not mandatory. There is a great irony here: that the VAD applicant, suffering with a life-limiting illness, may proceed through the entire VAD process unto death, never having seen a specialist in the care of patients suffering with life-limiting illnesses.

One legislative strategy is to mandate that all VAD applicants see Palliative Care as part of the VAD process. The immediate barrier to that approach is the fact that the majority of Palliative Care physicians oppose VAD. [12] That conscientious objection may extend to all aspects of the process of VAD including seeing an applicant *as part of a VAD process*.

Over many years, Palliative Care has distanced itself from VAD. Both commence with the suffering of an individual. But they have completely different destinations. The intention of Palliative Care is the conscientious attempt to comfort the patient with a life-limiting illness until their natural death. The intention of VAD is the deliberate cessation of a person's life or giving a patient the means to do so.

Rights and the VAD Bill

A common expression in the debate is the "right to die". The VAD Bill, if enacted will give a legal entitlement to VAD but not a right. The possession of a right denotes a duty in someone else to fulfil that right. There is no duty on doctors to provide VAD.

Another right sits here that is barely discussed but is recognised in international law : an international right to Palliative Care. That right has been seen by the WHO and UN Special Rapporteurs on human rights to be part of the overall international right to health and the right against cruel, inhuman and degrading treatment. [13] It is a shame that the VAD debate has been so controversial and dominated by a misstatement of rights when, beneath our gaze the right to the equitable provision of palliative care could have been the principal focus.

Conclusion

Any VAD Act faces an immediate problem. How does the law attempt to set down with any certainty the criteria of eligibility in an area – the end of life of a human being - that is replete with uncertainty, unknowability, vulnerability and, indeed, mystery ? As discussed above, medicine teaches us that all of these aspects are true.

The Act mandates the description but not the experience of Palliative Care. Participating VAD doctors may have minimal knowledge of this discipline. The tragedy is that the VAD process may trump the genuine conscientious attempt to care for a suffering pain with the highest expertise.

The enactment of VAD laws changes society and medicine irrevocably. The promotion of a right to the equitable provision of Palliative Care would be an entirely more appropriate objective.

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[1] White N, Reid S, Harris A et al. A systematic review of predictions of survival in palliative care: how accurate are clinicians and who are the experts ? *PLoS One* 2016;11: e016407.re.

[2] Glare P, Sinclair CT, Stone P et al. Predicting survival in patients with advanced disease. IN : Cherny N, Fallon MT, Kaasa S et al (eds) *Oxford Textbook of Palliative Medicine*, 5th ed, 2015.

[3] *Re T* [1992] 4 All ER 649.

[4] *Re MB* [1997] 1 FCR 426.

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

[6] Sumption J in *Nicholson* 2014 *UKSC* 38.

[7] Sumption J in *Nicholson* 2014 *UKSC* 38

[8] A/Professor Odette Spruijt. *MJA InSight+,* August 3 2020.

[9] Le BH, Philip J. *Medical J Australia* 2018;209:279.

[10] Portenoy R et al. *J Pain Symptom Management* 2006;32:532-540.

[11] Sykes N et al. *Lancet Oncology* 2003:4:312-318.

[12] Australian and New Zealand Society of Palliative Medicine (ANZSPM) *Position Statement on Euthanasia and Physician Assisted Dying.*

[13] Brennan FP, Gwyther E. Human Rights Issues. In: Cherny N et al (eds) *Oxford Textbook of Palliative Care*, 6th ed, 2021, Oxford University Press, Oxford.