

**LAW AND JUSTICE COMMITTEE**

**INQUIRY INTO THE PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021**

**Supplementary questions: Associate Professor Megan Best, Associate Professor of Bioethics, Institute for Ethics and Society, The University of Notre Dame Australia**

*Answers are to be returned to the Committee secretariat by 28 January 2022.*

**1. In evidence provided to the inquiry hearing on 13th December, Dr. Danielle McMullen, President, Australian Medical Association (NSW) said:**

**“We would undertake that the requirement for two separate doctors to both consult with the patient about their reasoning, intent and illness and to discuss with them all options available to them for their care, including voluntary assisted dying... .” (Hansard, page 5)**

**In evidence to the inquiry hearing on the same day Dr. Cameron McLaren, appearing as a private individual from Victoria said:**

**“I underwent the training [Voluntary Assisted Dying training] for two reasons: I did not want a patient for whom I had cared throughout their journey with cancer to have to seek external providers that they chose to pursue this option [Voluntary Assisted Dying]; secondly having been educated in medicine with a strong focus on patient-centred care, I felt that my opinion... .” (Hansard, page 67)**

**In evidence to the inquiry hearing on the same day Dr. Greg Mewett, Palliative Care Physician, Grampians Regional Palliative Care Team, Ballarat Health Services, Victoria said:**

**“My final comments would be that I find this [Voluntary Assisted Dying], as a palliative care doctor, patient-centred care... .”**

**and**

**“Palliative care is a style of care which, near the end of life, VAD is one type of choice in that care – they are not mutually exclusive.” (Hansard, page 69)**

**In evidence to the inquiry hearing on the same day Associate Professor Charlie Corke, Acting Chair, Voluntary Assisted Dying Board, Victoria said:**

**“I note that Dr. McLaren and Dr. Mewett both talked of patient-centred care. Really, the way in which we deliver health care can be considered as patient-centred care or medical-centred care or perhaps as legally-centred care or religious-centred care. There is a whole load of different ways we look at the way we deliver care. But, fundamentally, I think patients are wanting patient-centred care rather than any of those other options.” (Hansard, page 71)**

**Can you please comment on the implications for the professions of medicine and nursing and the overall medical, health and aged/residential care ecology of New South Wales by describing Voluntary Assisted Dying, as provided for in the *Voluntary Assisted Dying Bill 2021*, as “care” or “patient-centred care”?**

The issue here is whether killing a patient or prescribing poison so that a patient can kill themselves is any sort of care. The Oxford English Dictionary defines care as ‘protective oversight’. ‘Protection’ does not include assisting in the death of the one to be protected in the ordinary use of the term. I agree with the World Medical Association<sup>1</sup> and multiple medical and palliative care associations around the world that Voluntary Assisted Dying (VAD) is not medical care. It is contrary to medical ethics which have been in place for millenia and killing a

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<sup>1</sup> World Medical Association. WMA Declaration on Euthanasia and Physician-Assisted Suicide. Available on <http://www.wma.net/e/policy/e13b.htm> [Internet]. 2019. Available from: <https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/>.

patient is not within the traditional goals of care of medicine<sup>2</sup>. It therefore has no place in NSW medical, health and aged/residential care settings.

Medical practitioners have one of the highest rates of opposition to VAD in the community.<sup>3</sup> The goals of medicine and healthcare involve the preservation of life where possible and comfort care when cure is not possible, while neither hastening nor deferring death. VAD terminology seeks to provide a cloak of medical legitimacy to state sanctioned killing. The introduction of VAD, as provided for in the *Voluntary Assisted Dying Bill 2021* (the Bill) would therefore have a detrimental impact on the professions of medicine and nursing within NSW as it would put pressure on healthcare professionals to engage in behaviour for which they were not trained and to which they may well object. It leads to medical standards being turned upside down, as can be seen by Clause 133, where protection is given to protected persons who do not administer lifesaving treatment in the VAD setting.

Furthermore, it is known from the experience in Victoria since VAD was implemented in 2019 that the introduction of such a contentious issue within healthcare is divisive and creates 'considerable anxiety' for staff to the extent that psychological support is required to enable them to cope, even if they are not directly involved with the death.<sup>4</sup>

**2. Clause 6 of the *Voluntary Assisted Dying Bill 2021* deals with the matter of decision-making capacity. Sub-clause 6(2) deals with the specific matter of patients, for particular purposes of the legislation, having "presumed capacity". Can you please comment on the presumed capacity provisions (sub-clause 6(2)) of the Bill and in doing so, express your view about the appropriateness, or otherwise, of such provisions in a bill that provides for the establishment and operation of a Voluntary Assisted Dying procedure? Do the provisions pose any particular and specific threats and dangers to certain patient cohorts?**

This bill assumes that patients have 'presumed capacity', meaning that the onus is on the doctor to prove a patient *doesn't* have decision-making capacity. Given that, according to the eligibility criteria, we are dealing with a population who have advanced disease, this is a questionable assumption at the outset. Cognitive function is known to be impacted negatively by factors such as organ failure, medical treatments, and psychological morbidity. Research shows that 35% of people with physical and mental illness may lack capacity to make decisions about their health<sup>5</sup>. This is a complex diagnostic area, and a high level of skill and experience is required to make the assessment of whether mental capacity is sufficient for the purpose at hand<sup>6</sup>.

The need for this specialised assessment is grossly understated and underestimated in the Bill, with no requirement for the doctor to refer to a specialist to enable an accurate assessment to be made. Cognitive impairment, including delirium and neurodegenerative disorders, are often not recognised, even by doctors. Cognitive impairment, no matter how subtle, does definitely impact decision making capacity. It is well recognised that, the more significant the decision, the

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<sup>2</sup> Boudreau JD, Somerville MA. Euthanasia is not medical treatment. *Br Med Bull*. 2013 106:45-66.

<sup>3</sup> Baslev et al. 2020. Association between Danish physicians' religiosity and spirituality and their attitudes to end of life procedures. *J Relig Health*. 59:2654-2663.

<sup>4</sup> Digby R, McDougall R, Gold M, Ko D, O'Driscoll L, Bucknall T. Introducing Voluntary Assisted Dying: Staff Perspectives in an Acute Hospital. *International Journal of Health Policy and Management*. 2020:1-9.

<sup>5</sup> Breitbart, W. Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer. *Journal of the American Medical Association* (Dec. 13, 2000); Lepping, P, et al. Systematic Review on the prevalence of lack of capacity in medical and psychiatric settings. *J Clin Med (Lond)* 2015; 15(4).

<sup>6</sup> Agrawal M. Voluntariness in clinical research at the end of life. *Journal of Pain and Symptom Management*. 2003;25(4):S25-S32.

more care must be taken with capacity assessment, and the more caution is required in signing off on capacity. Clearly there is no more significant decision than the decision to end your own life. Referral to a psychiatrist or psychologist at the very least should be included in the Bill to ensure the decision to access VAD is valid, as was mandated in the 2017 VAD Bill which was rejected by the NSW parliament. As all eligible patients will have advanced disease, this should be a requirement for all participants.

**3. In evidence provided to the inquiry hearing on 8th December, Ms Penny Hackett, President, Dying With Dignity NSW said:**

**“The key feature of this law is choice. It is voluntary and no-one is compelled to be involved. Those who oppose VAD laws are not required to use them or to participate in the process.” (Hansard, page 3)**

**Can you please comment on what the actual meaning of the word “choice” is, as generally understood by the population at large and in the specific context of medico-health decision making?**

‘Choice’, according to the Oxford English Dictionary and as it is generally understood by the population at large, means deciding between possibilities. In medical decision-making terms, ‘choice’ denotes the self-determining decisions of a mentally competent adult, generally referring to the decision for a patient’s care. This is recognised as an expression of the individual’s autonomy.

In liberal societies, the principle of autonomy asserts that humans have a right to non-interference when making decisions about themselves. In healthcare decision-making, this principle is expressed in the legal requirement for the individual to give informed consent with regard to their own treatment.

However, while the concept of informed consent is widely supported, it has also been suggested that shared decision-making is a more likely to ensure true patient autonomy and better reflects the complexity and individuality of the relationship between the patient and the healthcare professional<sup>7</sup>. This is because the patient will depend on healthcare professionals to provide the information required for the patient to make a truly informed choice, as it is they who possess the required knowledge.

I would also like to comment that I believe that Ms Hackett is mistaken when she states that ‘no-one is compelled to be involved [in the VAD process]’. In the absence of human rights legislation in NSW and protection of conscience under the Anti-Discrimination Act, the conscience protections in this Bill are all there is for medical practitioners who hold to the traditional ethics of medicine. In clause 9, the Bill shields doctors from participating in the process but it is narrow; in clause 21(4) and (5), they must give the patient information that is approved by the Health Secretary – which is not yet available for scrutiny – and in clause 23(2)(h), they must report their objection and the reason for it to the VAD Board. This provision requires a doctor with a conscientious objection to provide official information to the patient, presumably information that will connect them to a “VAD coordinator.” This will be seen as akin to an obligation to refer by many healthcare professionals. Some medical practitioners will interpret the requirement to give information to the patient about the VAD process as being complicit in the act of VAD, so that this negates the promise of being able to conscientiously object, and represents compelling by the government for healthcare professions to be ‘involved’ whether they like it or not.

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<sup>7</sup> Kerridge I, Lowe M, Stewart C. Ethics and law for the health professions. 4 ed. Riverwood: Federation Press; 2013.

**4. In regard to the evidence referred to above in question 3 and the issue of “choice”, what would be the real and actual implications for citizens who, while potentially meeting eligibility and other requirements of the Voluntary Assisted Dying Bill 2021, are not able to have provided to them high quality, readily available palliative care, particularly with respect to those residing in rural, regional and remote NSW?**

In my response to question 3 above, I explained that ‘choice’ is defined as ‘deciding between possibilities’. The absence of high quality palliative care means that eligible persons, who will by definition be experiencing intolerable suffering (clause 16(d)(iii)), have fewer ‘possibilities’ when it comes to relief of that suffering. In fact they may feel they have no choice. The absence of palliative care could be argued to remove the possibility for a truly free choice to be made, as the patient may be told that there are no realistic options which allow relief of suffering in terms of available medical care. This makes a nonsense of talk about the bill being about ‘choice’.

Furthermore, while evidence shows that the wish to hasten death reduces in patients who receive good palliative care<sup>8</sup>, this effect operates only when the patient actually *receives* the care, not when they are just told about it. For those patients who live in jurisdictions where palliative care is not readily available, it is unlikely that they will have received a referral to palliative care, and therefore realized the true extent of options available to them. Therefore one could argue that their consent to VAD is not truly informed.

Is this Bill really attempting to reduce suffering? The rhetoric around euthanasia and physician assisted suicide tends to paint a picture of VAD as a last resort, but it is not the case if patients cannot (in the case of reduced or nil access to palliative care) explore alternative solutions.

**5. In the Victorian *Voluntary Assisted Dying Act 2017* there is a strict prohibition on the subject of Voluntary Assisted Dying being initiated with a patient (clause 8). An equivalent strict prohibition provision is not contained in the New South Wales *Voluntary Assisted Dying Bill 2021*. If a piece of legislation is to proceed from the New South Wales Parliament regarding Voluntary Assisted Dying, should it include a strict prohibition provision similar to clause 8 of the Victorian *Voluntary Assisted Dying Act 2017*?**

Yes. It is dangerous to allow the doctor to raise the subject of VAD due to the risk of coercion. Professor Brian Kelly, a psychiatrist at Newcastle University, NSW, has shown that the doctor’s attitude can have a powerful influence on the patient’s decision making<sup>9</sup>. This is compounded when the clinician has no experience or training in palliative and psychological care of patients. Even though, in the Bill, a healthcare professional can only raise the option of physician assisted suicide with a patient if they also discuss other options such as palliative care, what negative spin on the information about palliative care is a clinician without hope for the patient, or training in palliative care, and ideologically committed to physician assisted suicide, likely to communicate?

Furthermore, evidence shows that the power imbalance in the doctor-patient relationship is such that suggestions made by a doctor are often seen as directive rather than suggestive, and patients may relinquish their autonomy with the notion that ‘doctor knows best’<sup>10</sup>. If the

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<sup>8</sup> Breitbart W, Rosenfeld B, Gibson C, Pessin H, Poppito S, Nelson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial. *Psychooncology*. 2010;19:21-8.

<sup>9</sup> Association between clinician factors and a patient's wish to hasten death: terminally ill cancer patients and their doctors. Kelly BJ, Burnett PC, and Pelusi D *Psychosomatics*. 2004 45:311-318.

<sup>10</sup> Goodyear-Smith F, Buetow S. Power Issues in the Doctor-Patient Relationship. *Health Care Analysis*. 2001;9(4):449-62.

Parliament truly wants to avoid the risk of coercion, it should be illegal for healthcare workers to raise the topic of VAD with patients, as is the case in the state of Victoria.

**6. The Victorian *Voluntary Assisted Dying Act 2017* has, with respect to minimum requirements for co-ordinating medical practitioners and consulting medical practitioners, a requirement for the involvement of a medical specialist and an individual with relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed (clause 10). Equivalent provisions are not contained in the New South Wales *Voluntary Assisted Dying Bill 2021*. If a piece of legislation is to proceed from the New South Wales Parliament regarding Voluntary Assisted Dying, should it include provisions similar to clause 10 of the Victorian *Voluntary Assisted Dying Act 2017*?**

Yes. Without involvement of a medical specialist who is familiar with the disease, illness or medical condition expected to cause death in the person being assessed, there can be no assurance that eligibility of participants will be accurately determined. Doctors who are highly specialised in their field can say what the average life expectancy is for a particular illness, but even they can't say with any confidence what an *individual's* life expectancy is. Even more inaccurate will be a doctor who is not an expert in that field. And yet, this Bill puts patients at the mercy of doctors who might have inadequate skills or training to determine these very issues. Patients may decide to proceed with VAD with the erroneous understanding that their lifespan is more limited than is in fact the case. While there are recommendations that the practitioner refer to other doctors if they do not have the required information, how many of us know the extent of what we don't know?

There will also be a problem with informed consent to VAD. In the absence of a doctor with specialist knowledge about the patient's disease, there is no guarantee that the patient will be told of the full range of options available, and therefore the patient may not be making an informed choice. It is well known that the range of available options may vary according to the characteristics of the individual patient. However, there is no requirement that the healthcare worker discussing VAD even contacts the patient's current doctors, whether GP or specialist. No standard medical procedure would be legal in NSW with this level of information provision to the patient. Why is it allowed here?

Absence of a specialist in determining the patient's eligibility for VAD is further complicated by the recommendation for the use of telehealth in patient assessments (eg Clause 178(2)). Use of telehealth means that the practitioner does not even have to examine the patient in person. Doctors have had extensive experience with telehealth during the COVID-19 pandemic, and it is clear that it is difficult to accurately assess a patient through telehealth, particularly if you have not previously met that patient<sup>11</sup>. This is likely to be the case, as we know from the Victorian experience that in the first year of operation of the VAD Bill, the majority of VAD was administered by just four doctors<sup>12</sup>. The thought that a doctor would attempt to confirm the diagnosis and prognosis of a patient they have not previously met without even physically examining them would constitute medical negligence in any other setting. It is known that

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<sup>11</sup> Butow P, Havard PE, Butt Z, Kelly B, et al. Stakeholder perspectives on the impact of COVID-19 on oncology services: A qualitative study. Presented at Clinical Oncology Society of Australia Annual Meeting 2021.

<sup>12</sup> Willmott L, White BP, Sellars M, Yates PM. Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study. *Medical Journal of Australia*. 2021.

errors in diagnosis occurred during the time that euthanasia was legal in the Northern Territory<sup>13</sup>.

Please let me know if you would like me to expand further on any of these points.

Yours sincerely

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<sup>13</sup> Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally III Act, Northern Territory, Australia. *The Lancet*. 1998;352(9134):1097-102.