

## LAW AND JUSTICE COMMITTEE

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

#### Supplementary questions: Professor Margaret A. Somerville AM, Professor of Bioethics, Affiliate of the Institute for Ethics and Society, University of Notre Dame Australia:

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

#### Supplementary Question 1.

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”?

## Response

These statements raise two issues: i) what constitutes “patient-centred care”; and, ii) what is the nature of palliative care.

i) When Medicine was practised under a paternalistic model, the decision making and physician patient relationship was physician centred, that is, a “physician centred care” model. In other words it can be described as , “I, the physician, know best; I will decide on your treatment and care; you, the patient, need only to follow my instructions.” This relationship was based on “blind trust”, “Trust me the physician because I know best” – the patient’s blind trust in the physician. That model changed in the late 1970’s early 1980’s to a “patient-centred care” model that was based on “earned trust”. The physician and patient entered into a “therapeutic alliance” with the common goal of treating and caring for the patient and the physician had to earn and keep earning the patient’s trust. This model involved shared decision making implemented through the relatively new, at the time, doctrine of informed consent. Earning the patient’s trust required informing the patient to enable her and the physician to decide together what course to follow. “Patient centred care” does not mean that the patient has unlimited

autonomy and that the physician must provide whatever the patient wants, as some of the quotes above seem to assume. The physician-patient relationship is a fiduciary one, which is based on the physician's obligations to the patient of the utmost trust and confidence. For millennia Medicine has taught and practiced that this trust obligation requires that a physician must never intentionally inflict death on a patient.

ii) Physician assisted suicide and euthanasia and palliative care are based on opposite philosophical rationales and have conflicting informing principles. PAS-E postulates that the patient is "better off dead" and implements that outcome. Palliative care functions on a principle that all life is precious and of providing the best possible quality of life until natural death occurs. (See palliative care psychiatrist Dr Harvey Max Chochinov's book "Dignity Therapy" (OUP 2012)). Palliative care proposes that when cure is no longer possible, whole person healing is and it seeks to achieve that outcome.

PAS-E and palliative care are completely incompatible. PAS-E is not just an incremental step on a path we've already taken in palliative care, as PAS-E advocates argue. It is a negation of the philosophy and informing principles of palliative care. I also believe that we need to take the white coat off PAS-E if we are to make wise decisions about it. It is not medical treatment and should be kept out of medicine. If society wants it, there should be a separate, specially trained profession to provide it. These practitioners should not be physicians, consequently training physicians as described in the above quote should not be undertaken.

### **Supplementary Question 2**

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?

### **Response**

The law has a rebuttable presumption that all adults are presumed to have decision-making capacity, but for a decision as serious as having a lethal injection there should be strict safeguards to ensure this capacity, the presence of which can be difficult to judge even for professionals, such as psychiatrists trained to do so. It is one matter to have the capacity to decide to buy a new item of clothing, as compared with a decision to end one’s life. Capacity to provide the informed consent required for VAD, means the person must understand and appreciate the nature and consequences of their decision. Assessing this is complex. There is voluminous literature, accumulated over a fifty year period, with detailed analysis of what is necessary to establish a person’s capacity in any given circumstances.

There is also quite a lot of empirical research on what constitutes capacity to give informed consent. For instance, the more a patient agrees with the decision the doctor thinks is the right one, the more likely the doctor is to find the patient has capacity and the contrary is true if the patient and doctor disagree.

### Supplementary Question 3

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?

### RESPONSE

Choice does not mean unlimited choice, but rather choice within a range of options which are legal and “not contrary to public order and good morals” or “public policy” – these latter could be described collectively as not unethical courses of action. This kind of limitation is described in relation to freedom as “freedom in fetters”. In order to protect freedom, we must put some justified limits on its exercise. Moreover, choice does not mean that the doctor must provide whatever the patient wants, even if it would not be illegal to do so.

The main problem with Ms Hackett’s statement however is that it assumes that PAS-E does not affect anyone other than the patient. It affects many other individuals and the “ethical tone of society” and harms the “common good”. Please see my submission and subsequent oral evidence for further discussion of this issue. In particular, VAD is especially dangerous to vulnerable and fragile people.

#### Supplementary Question 4

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?

#### Response

The doctrine of informed consent requires that all reasonably indicated treatments must be offered to the patient for their consent to any given treatment to be valid. Consequently, even assuming PAS-E were a medical treatment, which I dispute, consent to it would not be a valid informed consent unless the patient were also offered fully adequate, high quality palliative care and freely chose not to accept this.

## Supplementary Question 5

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?

## Response

Despite the more egalitarian relationship between doctor and patient implemented through the “patient-centred care” model, there is a major power differential in the doctor–patient relationship and the doctor is an authority figure. Patients are strongly influenced by doctors’ suggestions and attitudes. We also need to keep in mind that one of the three most common reasons for asking for PAS-E is a feeling of being a burden on others. A doctor raising PAS-E could readily be interpreted by the patient as confirming their impression that they are a burden and hence influencing the patient to seek PAS-E. This is also relevant to the voluntariness of the patient’s informed consent which to be valid must be “free of coercion, undue influence and duress”. I am currently consulting on a Canadian case where this problem might be present.

## Supplementary Question 6

6. The Victorian Voluntary Assisted Dying Act 2017 has, with respect to minimum requirements for coordinating 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?

## Response

A decision to have one's life terminated or to end it oneself is arguably the most serious decision a person can take. It is also irreversible. Moreover, good facts are always necessary for good ethics, so even if one believes PAS-E can be ethical, that designation requires the best possible facts on which the decision about PAS-E is based. This means the Victorian requirements should be preferred. That said international experience attests to the fact that safeguards are quickly relaxed or abandoned as PAS-E becomes normalized in a society, consequently, we should not be hopeful that any stance short of prohibiting PAS-E will be protective of individuals and our society.