

Lilian Topic
 Secretary
 Legal & Social Issues Committee Parliament House
 Spring Street
 MELBOURNE. VIC. 3002

Re: Submission to Inquiry into End of Life Choices – Barbara Hayes

Thankyou for the opportunity to contribute to this Parliamentary Inquiry. My submission is a personal one, based on many years working as a Palliative Care Physician and eight years working as a Clinical Leader in Advance Care Planning. My PhD thesis (2011) was titled “Ethical CPR decision-making”. My experience, and my professional and research interests are particularly focussed on end-of-life decision-making and care. In this submission I would like to address the following two points, which are relevant to the Inquiry’s ‘Terms of Reference’.

1. Advance Care Planning and end-of-life decision-making

2. End-of-life care

I do not plan to directly discuss the complex topic of euthanasia in this submission as this has been well covered in submissions by Palliative Care organisations with which I am affiliated.

1. Advance Care Planning and end-of-life decision-making

The field of Advance Care Planning has been evolving over recent years (Emanuel and Scandrett 2010, White and Arnold 2011), and in Victoria, we are seeing a shift away from documenting treatment decisions in advance of a hypothetical illness, and a shift towards documenting values and principles that should underlie any future decision-making. This has particular relevance for a culturally and linguistically diverse state like Victoria, where there is potentially a range of normative ethical beliefs that are brought to decision-making at end-of-life (Johnstone and Kanitsaki 2009). There is consistent evidence for the value of appointing a trusted person as a medical substitute decision-maker. There is consistent evidence for the value of having discussions with that person, and the broader family, about things that the person wishes to be taken into account in medical decisions when they lack capacity to be directly involved. However, it can be very difficult to make detailed decisions about future illness when the circumstances are unknown and the decision must necessarily be incompletely informed; this is where Advance Care Planning is on less solid ground (Barnard 2002, Sudore and Fried 2010) and particularly challenging for those with poorer health literacy. The focus of the Victorian Department of Health and Human Services’ current Advance Care Planning Strategy is titled ‘Have the conversation’ (Department of Health Victoria 2014) and I believe that this is a wise choice for the reasons just discussed. The Department of Health and Human

Services is undertaking further Projects with consumers, including people from culturally and linguistically diverse communities to build on the work of the Strategy.

There are a number of factors that have influenced the development of Advance Care Planning systems. However, I venture to suggest that the need for Advance Care Planning also points to the need to have better clinician-patient discussions along the whole illness trajectory, involving the patient and family in discussions that educate about the valid option to not have recommended treatments, and education about approaching end-of-life for the patient when it is relevant. Good communication, and time for these conversations, must be a priority despite in the ever-increasing pressure to shorten length of hospital stays.

Some authors have suggested that the goal of Advance Care Planning is to better prepare the medical substitute decision-maker for the in-the-moment decisions that may need to be made at a time of future deterioration when the circumstances of the deterioration become known (Sudore and Fried 2010) and that there is no single 'right decision' (Barnard 2002). I find this a compelling argument for Advance Care Planning, although there will be some quite specific decisions, such as cardiopulmonary resuscitation, that might need to be made in advance because they need to be enacted without delay.

It is my observation that other states are addressing Advance Care Planning by making the Advance Care Planning documents more rigidly enforceable. However, I would encourage caution in this approach as a single, simple solution to any deficiencies in Advance Care Planning. Having said that, I recognise that one of the barriers to the usefulness of Advance Care Planning documents is that doctors are uncertain about the legal status of non-legislated Advance Care Plans. Clarification of this would be very useful and potentially improve the use of Advance Care Planning as a means for the person to have a voice in how they are cared for at a time of future deterioration.

2. End-of-life care

Our population is ageing. Medical success in treating or modifying illness means that many more people are living with chronic illness and with a longer trajectory of deterioration prior to death. The need for quality care during this time is of paramount importance. If a measure of a society is how well it treats its most vulnerable citizens, then there is a societal imperative to provide high quality health care and support to our frailer members of society, regardless of age. This means growing Specialist Palliative Care services to meet this need. Additionally, it means better education of all health professionals to be able to apply the principles of Palliative Care and to know when to refer to specialist Palliative Care services.

It is neither appropriate nor possible for every person with a life-limiting illness to be under the care of specialist Palliative Care services but there needs to be sufficient specialist Palliative Care: (i) to provide direct clinical care when needed; (ii) to provide consultant support when

needed; and (iii) to provide teaching to other health professionals about the principles of good Palliative Care, including quality communication.

The funding divide between state and Commonwealth is a real challenge for this area. Residential Aged Care Facilities and General Practice are both funded by the Commonwealth; there is only a small input into Residential Aged Care by state services. These Aged Care Facilities are increasingly expected to undertake end-of-life care but are often poorly staffed with respect to nursing and may have limited input from General Practitioners. Simple Palliative Care measures, such as administering opioids for pain become very difficult in the absence of nurses able to do this. This is an issue that must be urgently addressed and resolved if all Victorians are to have equitable access to quality end-of-life care.

It is concerning that there is considerable distrust of health services to be able to provide quality end-of-life care, and this has been illustrated in a number of the submissions. When there is funding for research, and better treatments to prolong life or to cure illness, it is essential that this is not done at the cost of compromising good clinical care for everyone, particularly those whose lives are reaching the final months, weeks or days. This is care that will ultimately benefit one hundred percent of all Victorians. Whilst there are a number of reasons identified in the submissions to promote legalised euthanasia, it is not acceptable that people should feel forced to seek death to escape suffering that should otherwise be treatable with current palliative care knowledge and skills, and with good general health care. Failure to provide treatment can occur when the clinicians lack skills, and it can also occur when clinicians don't understand the current law and when they fear treating symptoms because of a poorly founded anxiety that they might somehow be hastening dying. On the other hand, many patients and families also fear and distrust Palliative Care referral because they equate it with 'giving up' and sometimes as euthanasia. There is a need for further education of both clinicians and non-clinicians regarding: Palliative Care; the law at end-of-life; the limits to what can be achieved medically to prolong life; that more medicine is not always ethically or legally better medicine; communication skills for shared decision-making; and natural dying.

The two points that I have addressed capture the two groups of participants in end-of-life care and decisions: (i) the patient, their medical substitute decision-maker and family; and (ii) the clinicians and health services. They have shared, and complementary, roles that need to be supported to provide quality care of the patient who is approaching end-of-life.

This Inquiry is very timely and important. I am very happy to be contacted if you wish to further discuss aspects of this submission.

References

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- Johnstone, M.-J. and O. Kanitsaki (2009). "Ethics and advance care planning in a culturally diverse society." Journal of Transcultural Nursing **20**: 405-416.
- Sudore, R. and T. Fried (2010). "Redefining the "planning" in advance care planning: preparing for end-of-life decision making." Annals of Internal Medicine **153**: 256-261.
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