

## **Admin, LACO**

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**Subject:** FW: Submission to Joint Select Committee on End of Life Choices

**From:** Brien Hennessy

**Sent:** Thursday, 19 October 2017 11:21 AM

**To:** Joint Select Committee on End of Life Choices <[eolcc@parliament.wa.gov.au](mailto:eolcc@parliament.wa.gov.au)>

**Subject:** Submission to Joint Select Committee on End of Life Choices

Dear Joint Select Committee on End of Life Choices,

I would like to make a submission to the committee addressing two of the terms of reference-

1. assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;
2. examine the role of advanced health directives, enduring power of attorney and enduring power of guardianship laws and the implications for individuals covered by these instruments in any proposed legislation.

### **Background to this submission-**

I understand that many of the submissions made to the committee will be from the community who have had to watch their relatives die in circumstances that they feel could have been improved. We will all experience the impotent feelings associated with that situation at some point(s) in our lives. A natural response to those feelings of impotence is to try to improve the circumstances for those who will die in the future. I share this response, however, I make this submission from the viewpoint of a medical practitioner involved in the care of critically unwell people in a tertiary hospital, many of whom are dying. Our elderly patients don't appear to realise that they are dying. One day they are conducting their lives getting frailer and frailer when suddenly an intercurrent illness lands them in hospital. They rapidly become critically unwell and come to the attention of the Medical Emergency Team via the in-patient deterioration detection and response processes. At this point treatment decisions need to be made. The patient is unable to assist because they are too unwell. The next of kin - family are then engaged to assist with this decision making. Most often none of these people have ever discussed end-of-life wishes and there is either no advanced directive or it is not available at 02:00hrs during the resuscitation in the ward. Finding the correct person to represent the patients wishes is also a hit and miss affair. Difficult and vague communications then ensue in a time-poor environment where the outcomes are literally life and death.

In this hospital over the last 17 years of Medical Emergency attendances in the wards, the data reveals 300 people over 80 years-old became critically unwell as per the scenario above. Six of those people were alive 12 months later. Those six people spent their last year making almost weekly emergency department presentations and lived very diminished physical and cognitive lives with none returning to their former living circumstances during that period. I wonder how many of them would have chosen to be one of the six if they had known what lay ahead.

My role as an anaesthetist mostly becomes entwined with end-of life-choices when patients who are dying get booked for a surgical procedure. The patient and family are correctly told that there is some terrible pathology that, left untreated, will probably result in imminent death. One of the treatments could be an operation. With the operation the patient may have a chance of survival. Without the operation the patients chances of survival are even more remote. The patient and / or their NOK- family naturally see life and death as a binary outcome given such a choice, and therefore most consent for their relative to have an operation. The problem is that although death is a single outcome, life is not. Life can be living independently back at home with full physical and cognitive capacity with people you love or it can be living in a vegetative state in a nursing home- with

many shades of grey in-between these two extremes. Communicating this “third outcome” to a group of family members with disparate views whilst mum / dad lays dying nearby is a minefield. Families are usually not at their functional best at this time of stress. We call this a “goals of care” discussion where we try to describe what a good outcome and what a bad outcome might look like. Then we try to elucidate what the wishes of the patient might be given this situation before we negotiate a treatment path with appropriate boundaries. Although the family can’t mandate futile treatment, many will pressure critical care staff to become complicit in their demands to receive all treatments possible as a default position. This default setting may or may not have been the wishes of the patient- that remains unknown. This default position is not in the patient’s or community’s best interests as it is resource intensive and is ultimately unsuccessful. In my opinion, dying alone during resuscitation under anaesthesia in an operating room full of strangers, or shortly thereafter in an ICU or hospital ward is not a better death than comfort care in a hospital ward with family present. And unfortunately surviving critical care treatment in a debilitated state for a few months is the only other probable alternative. Herein lies the committees *raison d’être*.

**To specifically address the first term of reference-**

My experiences lead me to believe that we need to normalise conversations around death, dying and end-of-life choices in our community. I believe this because people don’t realise that they are dying until it is too late to think about an advanced care directive. It is their misinformed belief that they will somehow know that they have a terminal illness before their terminal event and they will gather the flock around at home and “conduct” the perfect death. The data shows that they are most likely to have a very different experience where they will die suddenly in a hospital or nursing home from a terminal event that they didn’t foresee. Therefore, to assist a person to exercise their preferences at their end of life, our community needs general education about how people are currently dying and that they need to speak to their family about their wishes before it is too late to do so. Clearly this can’t be legislated for. Ironically, it is a role for health promotion. What is a point for legislation however is that an advanced health care directive should not be limited to those who have chronic and/or terminal illnesses that they know about. Only a minority of people in my experience realise that they are dying of accumulated chronic illnesses. People need encouragement to have discussions with their family about their end-of-life choices and document those discussions in a format that is available when it is needed- on a hospital ward at 2am whilst undergoing resuscitation.

**To specifically address the second term of reference-**

The role of the advanced health care directives, enduring power of attorney, enduring power of guardianship should be crystal clear so that the difficult discussions at 2am are at least held with the correct person representing the patient’s wishes and are not vague in content. The clinical staff who attend pre-terminal events need to know who to speak with regarding the patients delegated wishes. The methodology for discovering this information needs to be such that it can be easily known by clinicians who have never met the patient before and are busy performing resuscitation. It cannot be a phone call or computer login away or it may as well be kept on the moon. Health IT in this state is an absolute disgrace. Therefore, the solution for availability of this crucial information needs to circumvent that.

I wish the committee luck in designing policy and legislation for this crucial project.

Regards,

Brien

Dr Brien Hennessy  
Head of Department of Anaesthesia