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21 July 2015

Ms Lillian Topic, Secretary, Legal and Social Issue Committee, Legislative Council Parliment House, Spring Street, EAST MELBOURNE 3002

Dear Ms Topic,

Re: Inquiry into End of Life Choices

The way that we care for people who are dying is integral to good healthcare and a compassionate and civil society. Providing holistic care in the last days, weeks or months of a person's life can help to minimise pain, anxiety, distress and grief for the patient, family and significant others.

The current legislation within the state of Victoria guides medical practice to assist those caring for patients during their end of life at Western Health. Staff at Western Health are guided by interdependent legal and ethical frameworks to provide the best holistic evidence based care for our patients and their families.

End of Life Care: Legal Framework

There are several documents that together provide the legal framework pertaining to end of life care in Victoria: the Enduring Power of Attorney (Medical Treament) (MEPOA) and the Refusal of Treatment Certificate. The MEPOA helps to identify an appointee/'person responsible' who has the legal authority to make medical decisions on behalf of the patient if the patient is unable to make the decision themselves. The Refusal of Treatment Certificate allows for a patient or their MEPOA appointee to refuse treatment with the exception of Palliative Care. To provide medical treatment once the Refusal of Treatment Certificate has been signed is medical trespass.

If the patient is unable to provide consent as to their treatment and no 'person responsible' is able to be appointed, contact is made with the Victorian Civil and Administrative Tribunal (VCAT) and a guardian is appointed by the Guardianship Board of VCAT to act in the best interests of the patient. If there are unresolved disputes about end of life care despite negotiations between patients/their appointees and hospital staff then occasionally it becomes necessary to involve the court system, including the Supreme Court of Victoria. Staff at Western Health do not see a strong case for major changes to the legal framework currently surrounding end of life care.

End of Life Care: Ethical Framework

The ethical framework of end of life care complements the legal concerns noted previously. Hospital staff have a duty of care to their patients. There are rights and responsibilities for both medical staff and patients, including the right (both legal and ethical) of a clinician (doctor, nurse, allied health practitioner) to not provide ineffective (futile) treatment.

Advance care planning refers to a pathway to support discussions with patients and/or their representatives about the patient's goals and wishes for medical treatment, particularly in relation to living with a chronic or terminal illness, and end-of-life care. Advance care planning (ACP) is an integral component of person centred care as it promotes open discussion between the patient and their health care team and increases the likelihood that their expectations of care being achieved.

Advance care planning and appropriate end of life care, including palliative care, are now included in the Australian Commission on Safety and Quality in Health Care National Standards (Standards1,9 and 12) These standards are likely to facilitate continual improvement of end of life care. The aim of Standard 12 is to ensure that high quality care is delivered to patients across the care continuum ensuring that within public health care facilities we manage the care of dying and deceased patients with dignity and comfort, and provide support to their families and carers.

In Victoria, unlike a refusal of treatment certificate, there are no legal documents entitled "advance care planning". Nevertheless, it would be challenging for anyone to disregard an advance care plan, provided that the treatment desired by the patient/their appointee is not medically ineffective (i.e. futile) therapy. Staff at Western Health do not see a strong case for major changes to the ethical framework currently surrounding end of life care and advance care planning.

Considerations for the future

Skilful end of life care and advance care planning are integral to an exceptional healthcare system. The ethical and legal frameworks for end of life care and ACP do not require major adjustments in Victoria. Rather, it is of concern that there are many patients that Western Health staff see that have not had access to timely, thoughtful end of life care and ACP. Patients can arrive at a hospital distressed, confused and ill; states of health that are antithetical to calm, purposeful end of life care discussions. It is not routine that healthcare clinicians do not wish to converse about end of life care, but often it is challenging to do so under time pressured constraints.

A limitation of end of life care acknowledged by many health care clinicians is the systematic communication of advance care planning documents between health care providers. If the patient does not have an advance care plan on the hospital alerts system and the patient lacks capacity, hospital staff are reliant on the patient's family/significant others or Residential Aged Care Facility to bring in the documents, or advise us of the patient's previously expressed healthcare preferences.

There is currently no statewide/nationwide data base to lodge or retrieve a patient's advance care plan and therefore there is potential for a patient to have an advance care plan that we are not aware of. Routine enquiry about prior advance care planning should therefore be part of any admission process. If the patient retains medical decision making competence, this is an opportunity to check the currency of any ACP documents. If the patient has lost medical decision making competence, prior advance care planning needs to be taken into account in any medical decision making.

Western Health services a rapidly growing, dynamic and multicultural population of over 800,000 people. Patients and families within Melbourne's western suburbs speak over 110 different languages. This has proved to be quite challenging to ensure that all of our patients are offered the same services, particularly intensive discourses, such as end of life care. We strive to provide individualised end of life care to meet the needs of each patient at this stage of their life. It is not that major changes are required to legislation, but that more resources are required to be provided to meet the ever growing demand for end of life care. It is likely that end of life discussions outside, rather than within of the hospital would be more beneficial. Convesations about end of life care between the patient, their appointee and the general practioner and/or skilled nurse practitioner could be rewarding. Consultation with relevant stakeholders such as patient representatives, general practitioners, palliative care clinicians, nursing home co-ordinators, hospital administrators would be useful to progess the important cause of end of life care.

Yours sincerely,

Assoc Prof Alex Cockram Chief Executive Western Health