Submission to the Standing Committee on Legal and Social Issues (Legislation and References):
August 2015

INQUIRY INTO END OF LIFE CHOICES

The Australasian College for Emergency Medicine (ACEM) welcomes the opportunity to provide feedback to the Standing Committee on Legal and Social Issues (Legislation and References) regarding its Inquiry into End of Life Choices.

ACEM is a not-for-profit organisation responsible for the training and ongoing education of emergency physicians, and for the advancement of professional standards in emergency medicine, in Australia and New Zealand. ACEM, as the peak professional organisation for emergency medicine in Australasia, has a vital interest in ensuring the highest standards of emergency medical care are maintained for all patients across Australasia.

ACEM strongly supports advanced planning of end of life (EoL) care that can improve the quality of life (QoL) of patients who are facing life-threatening illness or the final stage of their life. Research has shown that EoL care interventions can prove to be more beneficial if commenced early, and ACEM encourages broad community discussion regarding EoL care, limitations of medical interventions and treatment of those who are nearing the end of their life due to terminal illness or age, as well as the goals of EoL care.1

Palliative care is a component of EoL care and its primary aim is to improve the QoL of patients, as well as the families and carers of those facing life-threatening illnesses or approaching the end of their life.2 Palliative care focuses on the provision of pain management and relief of suffering through early identification and assessment, as well as services that can assist with the psychosocial or spiritual needs of patients and their families.3

ACEM notes that whilst managing death and dying is a routine part of work in the emergency department (ED), the practice of EoL care in the ED is traditionally undertaken for patients with an unexpected or acute injury caused by a catastrophic event and whose death is imminent, or patients presenting with an unexpected acute episode of a chronic illness.4 This practice of EoL care includes

2 Ibid.
3 Ibid.
minimising pain and suffering, reference to the Advance Care Directive (ACD) of the patient (if available) and withdrawing life-supporting treatment after discussion with carers/family members.

However, ACEM notes that the ED is now routinely being utilised as the default provider for EoL care, and in some cases palliative care, for elderly patients and those with a terminal illness. Residents from aged-care facilities are now comprising a significant proportion of ED presentations.\(^5\) ACEM identifies a number of causes behind this changing trend in the practice of EoL care.

### Lack of clearly defined EoL care options facilitated at the primary and residential care level

The *National Consensus Statement: essential elements for safe and high-quality end-of-life care (2015)* states that the health care that patients receive in the last stages of their lives can prove vital in minimising the distress and grief associated with death and dying for the individual as well as their family, friends and care givers.\(^6\) The National Consensus Statement also emphasises the need for patient-centred care in order to ensure that patients play a key decision-making role in EoL choices.\(^7\)

ACEM notes that residential aged care facilities (RACFs) are well situated within the community to provide patient-centred EoL care. RACFs can also provide outreach to the relevant primary care services needed by residents in order to manage their existing conditions, or assist in the management of their EoL care plan.\(^8\) Removing elderly patients from these facilities in order to provide EoL care within another setting, such as an ED, can be distressing and disorientating, and often exacerbates chronic conditions.\(^9\)

For patients with existing chronic conditions or terminal illness who wish to discuss or establish an EoL care plan, local primary care services, such as a General Practitioner (GP), can provide coordinated management of their condition, as well as a familiar setting in which expectations of EoL care can be discussed and managed. GPs also often act as the lynchpin of a number of other health services, such as palliative and other forms of complimentary care.\(^10\)

ACEM notes that, whilst residential and primary care facilities can provide well managed and coordinated EoL care to patients, elderly and complex ED presentations, particularly from RACFs, are increasing. Despite the benefits of well-planned EoL care, ACEM also notes that the focus on the patient as decision-maker at this stage of an elderly or terminally ill patients’ life is difficult to achieve in ED settings and often overlooked. Providing dignified EoL care is complex within the ED setting, as patients requiring such care often present due to an acute deterioration in their health. At this point it is often too late to discuss effective EoL options with the patient, as well as their family or caregiver(s). In this acute setting relatives often do not wish to make such difficult decisions.

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\(^{5}\) Julia Morphet, Keli Innes, Debra L Griffiths et al, “Resident transfers from aged care facilities to emergency departments: Can they be avoided?” *Emergency Medicine Australasia*, (2015): 1


\(^{7}\) Ibid, 6.

\(^{8}\) Morphet, Innes, Griffiths et al, “Residential transfers from aged care facilities,” 1.

\(^{9}\) Ibid.

and consequently resource intensive resuscitation and management is often commenced, and then ceased, contributing to the distress of the family and patient.

EDs are well equipped to provide care and facilitate access to external EoL care services, and are also increasingly focussing on how to educate their staff regarding EoL care conversations. However, ACEM notes that these discussions can and should occur prior to the onset of acute deterioration.

**Lack of clarity, confidence and resourcing at the primary care level**

Presentations to the ED by elderly patients and those with a terminal illness are often brought about by a lack of ACDs or documented discussions about realistic EoL treatment, along with inappropriate transfers to the ED from the primary or residential care settings.\(^\text{11}\)

ACEM notes that increasing ED presentations of elderly patients from RACFs, requiring EoL care, could be minimised through better resourcing of primary care providers. Patients with a terminal illness and who are approaching the end of their life could also avoid the ED for their EoL care needs by being provided with resources at the primary care level to plan and clearly outline their expectations and wishes for EoL care. A community campaign designed to increase the uptake of EoL care planning and raise public awareness that home-based, residential or community facilities are appropriate settings for EoL care to be delivered is also important. Ensuring that primary care providers are appropriately skilled and resourced to develop EoL plans is also critical to optimising the uptake and appropriateness of the plans.

Clearly defined EoL care options such as ACDs, and documented discussions with family members, carers and GPs regarding realistic treatment and inappropriate transfers to the ED can support elderly patients to remain within their home or RACF and receive EoL care. A clearly defined EoL care plan can also ensure that families and carers have an understanding of the patient’s wishes as well as realistic expectations of treatment and its limitations.

**Legislative changes**

ACEM supports the autonomy of patients to make their own informed decisions about EoL care and also supports the role of doctors in advising on what is acceptable practice regarding patients who are clearly approaching the end of their life. Patient and doctor understanding and management of EoL choices could be enhanced through a number of changes to the existing Victorian legislation.

**Advance Care Directives**

Whilst the *Medical Treatment Act 1988 (Vic)* provides the Refusal of Treatment Certificate, it only allows individuals to create binding written refusal of medical treatment for current conditions and does not allow for the refusal of medical treatment in advance of a medical condition.

ACEM therefore supports legislative change that mandates ACDs for all high-level care nursing home admissions, even if the patient does not have a current condition. Such change would ensure patient autonomy and avoid potential miscommunication between medical practitioners and family

\(^{11}\) Ibid.
members. ACEM also recommends that mandated ACDs be initiated for certain groups of patients, such as those with terminal illnesses or co-morbidities, when admitted to hospitals.

Such legislative change will ensure that GPs, Geriatricians and other health care providers are encouraged to dedicate time and resources to thoroughly and clearly discussing and documenting EoL care plans with their patients and families or carers. This will subsequently avoid miscommunication and ambiguity for all parties.

**Integrated Information Technology (IT) infrastructure**

The Queensland Health *Statewide strategy for end-of-life care (2015)* outlines a number of service directions intended to strengthen the capability and capacity of Queensland health services to support and assist those who are living with life limiting illness and dying.\(^{12}\) Service direction 4 of this strategy promotes the configuration of information and communication technology, with a goal of combining the range of service types in order to create a system responsive to individual patient EoL care needs.\(^{13}\) In order to achieve this, the Department of Health (DoH) has committed to trialling the addition of EoL care information into Queensland Health’s integrated electronic medical record system.\(^{14}\)

Victoria does not currently provide a formal registration system in order to ensure that ACDs are reliably retrieved and implemented at short notice, if required. As ACDs provide a clear explanation of the patient’s wishes, enable discussion of realistic treatment, and also assist in avoiding distressing ED presentations, ACEM would support legislative change that facilitates and encourages integrated and effective healthcare Information Technology (IT) infrastructure. Through the provision of a formal registration system, there would be less reliance upon the families and carers of patients approaching the end of their life to provide a physical copy of the ACD or documented EoL care plan.

IT infrastructure solutions are critical to all elements of health care. ACD’s represent a good example of a gap that needs to and can be filled through improved IT infrastructure. Rather than rely on (copies of) a single (paper) form, ACEM envisages an electronic system which enables healthcare workers in a number of locations to see (and, ideally, modify) a “single point of truth” ACD at any time of the day or night.

**Palliative care**

Whilst the *Medical Treatment Act* does not apply to palliative care, ACEM suggests that it is important that there is sufficient legislation concerning this aspect of EoL care.

A palliative approach, in which the QoL of patients facing life threatening illness or approaching the end of their life is improved, should be facilitated by legislation as a beneficial element in the broad EoL care plan of a patient, and should be made available to all who require it.\(^{15}\) ACEM also supports


\(^{13}\) Ibid, 9.

\(^{14}\) Ibid, 10.

\(^{15}\) Russ, Mountain, Rogers et al, “Staff perceptions of palliative care,” 1.
greater resourcing in order to improve home palliative care services as well as measures that strengthen relationships between GPs and palliative care organisations.

ACEM notes that many treatment decisions relating to patients who are reaching the end of their life involve balancing quality and duration of life. Medical interventions can discount a deterioration in quality if the duration of life can be maximised. For example, many surgical procedures cause a short term loss of quality of life but offer long term improvement, usually relating to both quality and duration. However, as palliative care seeks to maximise QoL and does not seek to impact upon the duration, many health practitioners struggle with causing, or allowing, a reduction in the duration of a patient’s life.

ACEM therefore encourages the introduction of legislation that protects practitioners in situations in which a decision has been made that prolonging life is no longer the primary aim, and optimising the QoL of the patient is the only significant and/or realistic goal.

Community education
The Statewide strategy for end-of-life care also supports engagement with the broader community by encouraging open conversation about death and dying and the choices that can be made in planning this part of life.15

ACEM strongly endorses the need for improved general community awareness of EoL care, and encourages the introduction of a community campaign that facilitates greater discussion of EoL and palliative care. The emphasis of these discussions should focus on documenting what patients view as acceptable or unacceptable outcomes on their QoL, when facing a life-threatening condition or terminal illness, rather than including or excluding certain therapies or interventions, such as resuscitation.

ACEM suggests that by approaching community education in this manner, patients (and their families and carers) will be able to consider the impact that intervention could have upon the quality of the final stages of life.

Thank you for the opportunity to provide feedback to the Standing Committee on Legal and Social Issues (Legislation and References) in its Inquiry into End of Life Choices. If you require any clarification or further information, please do not hesitate to contact the ACEM Policy Manager

Yours sincerely,

DR ANTHONY CROSS
PRESIDENT

15 State of Queensland (Queensland Health), Statewide Strategy for end-of-life care, 4.